

YALE MEDICAL LIBRARY



3 9002 08676 2425

DECIDING FOR OTHERS :
RIGHTS AND RESPONSIBILITIES IN MEDICAL ETHICS

PATRICIA MARY POWELL

1987

YALE



MEDICAL LIBRARY

Permission for photocopying or microfilming of

" Deciding for Others: Rights & Responsibilities in
Medical Ethics " for the

purpose of individual scholarly consultation or reference is hereby granted by the author. This permission is not to be interpreted as affecting publication of this work, or otherwise placing it in the public domain, and the author reserves all rights of ownership guaranteed under common law protection of unpublished manuscripts.

Patricia M. Powell

(Signature of author)

PATRICK M. POWELL

(Printed name)

March 16, 1987

(Date)



Digitized by the Internet Archive
in 2017 with funding from
Arcadia Fund

<https://archive.org/details/decidingforother00powe>

DECIDING FOR OTHERS:
RIGHTS AND RESPONSIBILITIES IN MEDICAL ETHICS

A Thesis Submitted to the Yale University
School of Medicine in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Medicine

by

Patricia Mary Powell

1987

Med Lib

T113

+Y12

5551

ABSTRACT

DECIDING FOR OTHERS: RIGHTS AND RESPONSIBILITIES IN MEDICAL ETHICS

Patricia Mary Powell

1987

This paper addresses two questions within contemporary medical ethics. First, how do we make treatment decisions for seriously ill, incompetent patients? Second, how ought we to make these decisions? Most medical ethicists analyze these questions using the legal model, and therefore strive above all to protect autonomy and the patient's rights. This approach fails to incorporate the concerns of many physicians and family members, who are concerned not only with rights, but also with such subjective factors as pain, and the patient's sense of relation to the community. Physicians, however, have often been unable to formulate decisions which are clear and principled, and yet incorporate this subjective information.

By turning away from the legal model, with its ethics of rights, and toward the ethics of responsibility, we can derive principles which will aid physicians and families in making decisions for incompetent patients. This new ethical framework allows us to describe more accurately the relevant factors in decisions for incompetent patients. In addition, the ethics of responsibility shows us how to improve decisions in this crucial area of medical ethics.

Acknowledgments

First of all, I would like to thank my husband, Jim Shapiro, for his support and encouragement, and for his tolerance of the considerable domestic upheaval occasioned by this paper. Thanks also, to my classmates Lynn Street and Laura Kuckes for their wisdom in countless discussions of the ethical and emotional aspects of medicine, and of learning to become a doctor. Last, I would like to thank Bob Levine, the most dedicated teacher I have known, without whom there would be no thesis.

TABLE OF CONTENTS

Chapter I: Introduction.....	1
Chapter II: The Historical Context.....	6
Chapter III: Autonomy Questioned.....	23
Chapter IV: Theories of Moral Development.....	30
Chapter V: Implications for Medical Ethics.....	49
Chapter VI: The Ethics of Responsibility.....	70
Chapter VII: John Storar.....	88
Chapter VIII: Conclusion.....	112
Bibliography.....	115

Chapter I: Introduction

This thesis will attempt to shed light on two difficult questions within medical ethics. First, how do we make treatment decisions for seriously ill, incompetent patients? Second, how ought we to make these decisions?

I do not pretend to ask these questions in an entirely neutral manner, for they are prompted by certain troubling observations. Physicians and members of the public criticize the legal reasoning used in analyzing these decisions as being poorly suited to the task. The adversarial nature of legal proceedings, as well as the very neutrality and objectivity for which the law strives, fail to address the often subjective and emotional factors which may be pivotal in these dilemmas.

Physicians, who may sense keenly the short-comings of the legal model, are themselves unable to articulate clearly more appropriate principles for making these decisions. Confronted with the pain of patients and their families, and yet taxed by their perceived duty to pursue a cure with ever slimmer hopes of success, physicians flounder, failing to reconcile conflicting obligations. Thus we witness what doctors and lawyers have both identified as a persistent inability among physicians to name the principles by which they arrive at treatment decisions for incompetent patients.

Medical ethics ought to be a source of help to the

physician, by articulating and defining principles for decision-making. However, ethics often falls short of this goal. The main voice in the literature of medical ethics today emphasizes unduly the language and concepts of the law. The principles most frequently upheld in guiding decisions for all patients, including incompetent ones, are directed at preserving autonomy and patients' rights. Such concepts are cruelly inappropriate when applied to patients like Karen Quinlan, who are wholly unable to exercise autonomy or to assert any right. And yet without a trace of irony, the removal of a respirator from Karen Quinlan is described by one eminent ethicist as a "triumph of autonomy." There is a disquieting gap between the way many ethicists describe decision-making for incompetent patients, and how it is experienced by physicians and family members. Not surprisingly, the answers supplied by the ethicist seem often not to match the questions asked by families and doctors.

Is there any way to improve the fashion in which these decisions are formed? I believe there is, by turning away from the legal model, with its emphasis on rights, autonomy, and confrontation. The point is not, however, for doctors to chastise lawyers for the adverse impact of law on medicine, nor to suggest that these decisions are made excellently when doctors are left on their own. Indeed, the case which we shall examine most closely and criticize most harshly, that of John Storar, was one in which the courts sided with the physicians, to the disadvantage of the patient. In fact, doctors too often assign

elsewhere the blame for medicine's inadequacies. It is we who must strive to articulate our responsibilities in a way that incorporates the kindness and humanity that exemplifies medicine at its best, while delineating principles which are clear, and accessible to public discussion. If we cannot do this, it is with ourselves we must find fault.

Such principles, at once kind yet clear, can be subsumed within the ethics of responsibility, which contrasts with the legal system's ethics of rights. In describing the ethics of responsibility, I hope to provide a view of medical decision-making that is more accurate than the legal description, in that it acknowledges the impact of such subjective factors as emotion and pain. But beyond this sharper picture of reality, I hope also to indicate the direction we may take in striving for an ideal. That ideal cannot be realized, however, unless physicians accept responsibility for promoting among themselves clear thinking on these painful issues. In addition, we must help the public understand more fully the limitations of medicine at the end of life, and the distinction between decisions which are purely technical, and those which require ethical and moral evaluation.

The Plan of the Thesis

In order to answer our two questions about decision-making for incompetent patients, we will proceed according to the

following plan. In Chapter II, we will set the questions in their historical context by briefly reviewing major forces that have shaped medical ethics. In particular, we will look at the emergence of autonomy as a central concept in reasoning about medical dilemmas. In chapter III, we will examine some of the flaws of this standard approach, especially as it applies to incompetent patients. Then, in chapters IV and V, we will examine the work of two psychologists, Lawrence Kohlberg and Carol Gilligan, and apply some of their insights about moral development to the context of medical ethics.

The Ethics of Responsibility, the subject of chapter VI, is an effort to formulate a new ethical model, which will respond to criticisms of the old model and incorporate concepts not expressed within the traditional framework. We then discuss, in chapter VII, a particular legal case involving the withdrawal of life-sustaining treatment in an incompetent patient. We investigate how the court decided, and how one might have improved the outcome by reasoning within the ethics of responsibility. Chapter VIII summarizes conclusions and recommendations.

Before we begin our investigation, let us provide a few ground rules about the use of language in medical ethics. There are a few words that persistently arise in discussions such as the one we are about to undertake. Examples include words like "terminal," "heroic," and "extraordinary." Unfortunately, definitions of these words vary from author to author, making

their interpretation impossible. Rather than provide a set of definitions for this paper, I have followed the example of some recent writers, and have attempted to avoid these terms as much as possible. In some instances, this effort has meant the addition of explanatory phrases in place of one of these ill-defined words. I ask the reader to bear with me in this effort to attain greater clarity.

Chapter II: The Historical Context

The problem of making treatment decisions for incompetent patients has attracted an extraordinary amount of attention in the last decade. No doubt the reason lies in part in the great number of life-sustaining and life-saving treatments which are newly available. Fifty years ago, physicians and families chose among relatively few possible interventions for seriously ill patients. Since that time, intensive care units, respirators, defibrillators, and a rapidly expanding array of antibiotics and ingenious means for delivering nutrition have become commonplace. One reason that the problem has become more acute, therefore, is that there are more interventions to argue about.

However, the impact of new technology cannot fully explain why the debate stirs such passion. New medical treatments have always been proposed, and physicians have always, more or less heatedly, debated the merits of new and old regimens. Certainly this was true in 1871 when George Eliot wrote Middlemarch, in which the ambitious young Doctor Lydgate provokes the ire of his peers with such radical innovations as the stethoscope.¹ Thus, it is not just new technology that makes this problem contemporary. In any era physicians and families could have publicly debated the merits of continuing or withdrawing

¹ George Eliot, Middlemarch, Middlesex, England, Penguin Books, 1985, (1871), p.371.

therapies, yet they did not. What has changed, then, is that doctors and families do in fact debate these decisions, and in an unprecedentedly acrimonious and public fashion.

When one person is granted sole and unquestioned power to make a decision, there is little room for public debate about that decision. Historically, doctors felt that such exclusive decision-making power was not only their prerogative, but their obligation. This belief reflects an ancient tradition within medical ethics which emphasizes a benevolent protectiveness of doctors toward their patients.

In the Hippocratic Oath doctors swear to protect patients from harm and injustice, and to work for the benefit of the sick, as defined by the doctor. No reference is made to the possibility of a disagreement between doctor and patient as to what constitutes the patient's best interest. The Hippocratic Oath springs entirely from the doctor's point of view. It not only does not admit the possibility of argument, it ignores the existence of the patient's opinion. Thus, within the Hippocratic tradition, doctors are active, and patients are passive; doctors are subjects, while patients are objects. They are objects to be treated with the utmost care, but objects nonetheless.

This benevolent arrogance was perpetuated in more recent medical codes of ethics. Thomas Percival's Medical Ethics, published in 1803, reaffirmed the physician's obligations of beneficence and nonmaleficence, without discussing the idea of the patient's independent point of view. For instance, Percival

concurred with the practice of not revealing to patients their unfavorable prognoses unless "absolutely necessary." Doctors were to decide what information patients ought to know. The AMA, when it adopted its first code in 1847, drew largely from Percival's statements, although adding a few phrases designed to underscore the physician's authority.²

This tradition was biased toward the doctor's viewpoint and allowed physicians unfettered authority in exchange for benevolent supervision. It was bound to run afoul of modern legal notions of individual liberty and self-determination. Thus, the law entered the realm of medical ethics, and became a new shaping force.

Although earlier examples exist, two celebrated instances of the legal influence on medical ethics occurred in this country in the early twentieth century. In 1905, Mrs. Parmelia Davis, suffering from chronic epilepsy, was referred to Dr. Pratt, an authority on the subject. Dr. Pratt determined that a total hysterectomy was the treatment of choice for Mrs. Davis' epilepsy, and then performed the operation without ever explaining its nature to Mrs. Davis. When she learned that her uterus and ovaries had been removed, she sued, not because the treatment was inappropriate, but because she had not been warned. The doctor explained that he had not informed her because he

² Both Percival's Medical Ethics and the AMA code are discussed in: Jay Katz, The Silent World of Doctor and Patient, New York, Macmillan, Inc., 1984, p.17. Katz provides an excellent analysis not only of the evolution of codes of medical ethics, but also of informed consent.

"wished her to come to the operating room without violence." The doctor claimed that by consenting to treatment, the patient implicitly gave her consent to any procedure the physician deemed necessary. The court disagreed. Indeed, the judge found that to operate without permission was a violation of the patient's bodily integrity³.

The case of *Schloendorff v. The Society of New York Hospital*, in 1914, concerned another instance of an operation performed without permission. In this case, Mrs. Schloendorff had agreed to a pelvic examination under anesthesia, while insisting that no operation should take place. Despite her previously stated wishes, the physician proceeded to remove a fibroid tumor from the uterus. In his decision, Justice Cardozo produced the famous statement: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body..."⁴ This decision provided a springboard that helped clearly establish in common law the competent patient's right to refuse treatment.

Such judgments established more than a single right; they changed the vocabulary of medical ethics. The new language of medical ethics became the language of law, i.e., the language of rights. The change was more than just semantic, however, for it marked the entrance of law as a new force in medical ethics. It also introduced a profound tension between two viewpoints in

³ *Pratt v. Davis*, 118 Ill. App.161 (1905).

⁴ *Schloendorff v. New York Hospital*, 211 N.Y. 125 (1914).

medical ethics. One, older and more intrinsically medical, reflects the Hippocratic tradition of benevolent despotism. The second, a newer legal viewpoint, emphasizes the rights of individuals.

Autonomy's Rise

The legal emphasis on individual rights grew out of the political philosophy of the eighteenth and nineteenth centuries. In particular, the philosophy of Immanuel Kant influences the notion of individual rights in contemporary medical ethics. Kant based his ethical system on the categorical imperative, also known as the principle of respect for persons. One version of this principle is as follows: "Act so as to treat man, in your own person as well as in that of anyone else, always as an end, never merely as a means."⁵ Persons deserve respect in so far as they are rational beings whose will is autonomous. Thus autonomy, derived from the Greek autos (self) and nomos (rule), is exhibited by one who formulates his own moral laws, and is not constrained by factors such as fear or appetite⁶. A person's own desires and emotions are seen as external influences on the will, which is defined by Kant as a purely rational capacity. Autonomy, based entirely in reason, is for Kant the basis of respect for persons. All other rights and privileges stem from

⁵ Immanuel Kant, "Metaphysical Foundations of Morals," in The Philosophy of Kant, ed. by Carl J. Friedrich, New York, Modern Library, 1949, (1785), p.178.

⁶ Ibid., p.187.

this central concept of autonomy.

A different view of autonomy emerges from John Stuart Mill's writings in the nineteenth century. Mill stresses freedom of action, rather than of the will alone. He insists that autonomous persons must be free to choose courses of action which may run counter to societal conventions, as long as other persons are not harmed. In defining the relation of individuals to the community, Mill is concerned primarily with what society may rightly compel individuals to do. He summarizes the individual's obligations to society thus: 1) to act so as not to injure the rights of others, and 2) to bear a share of the labor necessary to defend society from injury and molestation.⁷ Thus, Mill emphasizes negative freedoms; autonomy becomes the right to be let alone.

For the purposes of this essay, we will define autonomy as the freedom of the individual to act on his moral beliefs without the physical or psychological constraints of others⁸. This modern definition of autonomy, based on that of Beauchamp and Childress, differs from Kant's in that it allows a role for non-rational factors in autonomous choice. The statement is phrased so that actions influenced by emotion could be considered autonomous. Beauchamp and Childress define as external only that

⁷ John Stuart Mill, On Liberty, Middlesex, England, Penguin Books, 1976, (1859), pp.141-2.

⁸ Tom L. Beauchamp and James F. Childress, Principles of Biomedical Ethics, New York, Oxford University Press, 1983, p.59.

which comes from other persons, whereas Kant defines as external those forces within the person which are not wholly rational. According to all these definitions, however, autonomy is the basis of respect for persons, and for the rights which are contingent upon this respect.

Autonomy has played a crucial role in the development of medical ethics in the twentieth century, not just for patients, but for research subjects as well. The importance of autonomy was quite evident from the codes of medical ethics which emerged from the trial of Nazi doctors at Nuremberg. Shocked by experiments conducted on prisoners, physicians and others were driven to elucidate the necessary ethical conditions for research on human subjects. The first of the basic principles enumerated was that "the voluntary consent of the human subject is absolutely essential."⁹ The code then stipulates that consent is not voluntary unless the person may "exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion...."¹⁰ In addition, consent must be based on knowledge of the experiment's nature and purpose, and any hazards it might entail for the subject.

It is of historical interest to note that the Nuremberg Code was not the first attempt to formulate ethical guidelines

⁹ Nuremberg Code, 1949, quoted in Beauchamp and Childress, p.339.

¹⁰ Ibid.

for human experimentation. Indeed, legally binding standards were in effect in Germany during the Third Reich. These rules specifically require informed consent for both "New Therapy" and "Human Experimentation." Although informed consent might be waived for new therapy "in urgent cases," no such exceptions existed for non-therapeutic experimentation. Thus, "without consent, non-therapeutic research [was] under no circumstances permissible."¹¹ Although the Nuremberg Code focussed public attention on the need to clarify and enforce codes of medical ethics, it was not, although it is often described as, the first attempt to accomplish this task.

The World Medical Assembly revised and expanded the concepts of the Nuremberg Code, adopting new guidelines in 1964. The new code continued to stress the importance of autonomy and thus of informed consent. Specific injunctions were included that potential subjects be:

adequately informed of the aims, methods, anticipated benefits and potential hazards of the study and the discomfort it may entail. He or she should be informed that he or she is at liberty to abstain from participation in the study...[or] withdraw...consent to participation at any time.¹²

This statement, which became known as the Declaration of Helsinki, further clarified the rights of research subjects,

¹¹ Hans-Martin Sass, "Reichsrundschreiben 1931: Pre-Nuremberg German Regulations Concerning New Therapy and Human Experimentation", Journal of Medicine and Philosophy, 8 (1983), p.106.

¹² Declaration of Helsinki, 1964, quoted in Appendix II, Beauchamp and Childress, p.343.

which derive from the principle of autonomy.

The Declaration of Helsinki served not only to define the rights of research subjects, but to draw attention to them. It became possible, with guideline in hand, to examine experiments and decide whether or not they in fact complied with the stated ethical principles. Not surprisingly, various experiments were found wanting in this regard.

Among the most controversial of these experiments was the Tuskegee syphilis study. This study commenced in 1932 under the auspices of the U.S. Public Health Service, and was not terminated until 1972. Some 400 black male residents of Macon County, Alabama, were enrolled in an experiment to observe the course of untreated syphilis. Physicians at the time knew the grave consequences of untreated syphilis, and believed that an effective treatment existed in arsenic therapy. The subjects were not warned that effective therapy existed, and that their participation in the experiment therefore posed an unnecessary risk to them. Thus, they were not informed of the treatment options either at the start of the study, or in the 1950's, when penicillin proved to be both unmistakably effective and widely available.

Indeed, the subjects were not even informed that they were in an experiment. They believed that they were being treated without charge by government doctors. It is true that they were not charged, but neither were they treated. In fact, the researchers circulated a list of names of participants to local

health facilities and to the Army, in which some of the subjects served, and requested that these men not be treated for syphilis because of their participation in the study.

Nor was the Tuskegee study a brief aberration. Although its findings had been reported in the scientific literature sporadically over the years, the study was not widely known until word of it appeared in the national press in 1972. HEW then convened a panel, but by the time this group issued its condemning Final Report a year later, between 30 and 100 men were estimated to have died directly as a result of advanced syphilis.¹³

The Tuskegee study, rife with racism, deceit, and the decades-long abuse of a disadvantaged rural population stands as an unusually chilling example of how wrong physicians could be in their treatment of research subjects. These doctors honored neither the Hippocratic tradition of nonmaleficence, nor the rights-based tradition of informed consent. Although conceived in the 1930's, one cannot lay the blame entirely on the thoughtlessness of an earlier generation, for the study was reviewed and continually funded by the Public Health Service throughout its forty year history. The public outcry following the press's exposure of the study indicated that such practices would not be tolerated.

¹³ Allan Brandt, "Racism and Research: The Case of the Tuskegee Syphilis Study," The Hastings Center Report, December, 1978, pp.21-9.

Thus, by the early 1970's there emerged a clear conception of the rights of research subjects as autonomous persons deserving of respect. The rights of patients developed along parallel lines, particularly stressing the right to informed consent¹⁴. In 1973, the American Hospital Association summarized these developments in the Patient's Bill of Rights. The Bill lists and describes such rights as that to "respectful care," informed consent, and confidentiality. Interestingly, in its concluding paragraph, the Bill states that, "No catalog of rights can guarantee for the patient the kind of treatment he has a right to expect." Therefore, the hospital must structure all its activities in order to ensure "above all, the recognition of [the patient's] dignity as a human being. Success in achieving this recognition assures success in the defense of the rights of the patient."¹⁵

Standards for Decision-Making

It is against this historical background that the standards of decision-making for incompetent patients developed, and are still evolving. We will review them as they now exist. Competent patients, i.e., those of "adult years and sound mind" have the right, clearly established in common law, to refuse any

¹⁴ see Jay Katz, Silent World, especially chapter 3.

¹⁵ American Hospital Association, 1973, quoted in Appendix II, Beauchamp and Childress, p.338.

treatment¹⁶.

When we are confronted with a once-competent patient, we must search for previous expressions about what treatments he thought appropriate in the event of becoming incompetent. Rarely, we discover a patient who has left a detailed account of these views, and then we use the substitute judgment standard. Brother Fox is an example of such a patient. In the context of a formal discussion in his religious community, 83 year old Brother Fox stated, in reference to the Quinlan case, that he would not want "heroic" measures, such as artificial respiration, if he were irreversibly comatose. He repeated these views to his superior before entering the hospital for a herniorrhaphy. Brother Fox suffered complications of general anesthesia, and went into a coma¹⁷. The court appropriately used the substitute judgment standard and removed the respirator. This standard, thus, is correctly used for patients who, when competent, expressed clear views on treatments they would find acceptable when incompetent.

Proxy decisions, i.e., decisions for the incompetent, are more difficult for patients who were never competent, or who never stated views on life-sustaining treatment. According to the President's Commission, we ought not to use the substitute judgment standard for such patients, since we are not in a

¹⁶ Schloendorff; see ref. 4.

¹⁷ Matter of Eichner, on behalf of Fox, 438 NYS 2nd Series, 266; March, 1981.

position to know what they would do if competent. We must instead use the best interest standard¹⁸.

The best interest standard is defined, according to the President's Commission, "by reference to more objective, societally shared criteria...[It] does not rest on self-determination but solely on protection of patient's welfare."¹⁹ This standard does not set out to maximize autonomy, but protection. The Commission goes on, however, to add that the surrogate decision-maker should "...choose a course that will promote the patient's well-being as it would probably be conceived by a reasonable person in the patient's circumstances...."²⁰

The best interest standard, due to its use of "objective criteria," as "conceived by a reasonable person," has not always been adequate to its task. In the Saikewicz case, for instance, the judge considered and rejected the best interest standard. Joseph Saikewicz was a 67 year old, severely retarded, non-verbal and permanently institutionalized man who bore the diagnosis of acute myeloblastic monocytic leukemia. If Saikewicz received chemotherapy, he would have about a forty percent chance of a

¹⁸ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment, Washington, D.C., U.S. Government Printing Office, 1983, p.134.

¹⁹ Ibid., p.135.

²⁰ Ibid., p.136.

remission, which might last from two to thirteen months²¹. Most patients with this form of leukemia do elect chemotherapy. The judge felt that the most common decision, that made by most people, must be the "reasonable" one. Yet he realized that other people were not like Saikewicz; they could understand the reason for their painful treatment, whereas he could not. Therefore, they were not truly "in his circumstances." The judge was extremely reluctant to impose on Saikewicz a painful therapy for which he could understand neither the nature nor the purpose.

On a practical level, it would be hard to administer the treatment without Saikewicz's cooperation. Furthermore, the judge wished to preserve for Saikewicz the possibility of refusal, which each one of these competent patients had. Thus, the judge tried to incorporate into his decision subjective factors which he rightfully considered to be central. The only method he could devise was to reject the unyieldingly objective best interest standard and adapt the substitute judgment standard, although Saikewicz had never been competent. The judge asks us to indulge in the fiction that Saikewicz could for an instant be competent, yet realize that he would soon, once again, be permanently incompetent. He theorizes that Saikewicz would then choose to forego chemotherapy. This bizarre approach attempts to correct the flaws of the best interest standard by including important subjective factors in a decision for a never-

²¹ Matter of Saikewicz, Massachusetts Supreme Judicial Court, November, 1977.

competent patient.

The Saikewicz decision was written several years before the President's Commission's recommendations on the use of the substitute judgment and best interest standards. If the Supreme Court of Massachusetts were deciding the case today, they would know that substitute judgment was "wrong" for Saikewicz, but they might still be dissatisfied with the best interest standard. Neither standard accommodates the need to include subjective factors when deciding for never competent patients. Thus, the standards are inadequate. We shall need to develop, therefore, within the ethics of responsibility, standards which will accommodate subjective criteria in decisions for the never-competent.

The legal standards make the assumption that when a patient cannot competently tell us of his subjective experiences, we cannot know them, and so must disregard them in our decision-making. Yet even persons with severely compromised competence do have subjective experiences, and these can be known by us to an extent. For instance, when Mary Hier, a ninety-two year old, chronically demented patient persistently removed her gastrostomy feeding tube, she was indicating that the tube was painful to her. The Massachusetts court placed considerable credence in these communications, although they were those of an incompetent²². Thus, the court decided not to force Mrs. Hier to undergo surgery for the reimplantation of her tube, even though

²² In the Matter of Mary Hier, 18 Mass. App. 200 (1984).

she would then lack any route by which to receive life-sustaining nutrition.

If we were to ignore subjective factors, we would be categorically denying information which ought to figure heavily in our decisions. For it is in this realm of the subjective in which suffering occurs, and the incompetent are in no way excluded from suffering. Eric Cassell has commented on the need to improve our understanding of suffering:

Attempting to understand what suffering is and how physicians might truly be devoted to its relief will require that medicine and its critics overcome the dichotomy between mind and body and the associated dichotomies between subjective and objective and between person and object.²³

The acknowledgment of suffering is crucial for medical decisions within the ethics of responsibility; such knowledge requires that we strive to understand the communications of the incompetent.

Thus, we have briefly examined some of the forces which shape contemporary medical ethics. The Hippocratic Oath stressed the beneficence of autonomous physicians caring for dependent patients. Many have come to see this as a paternalistic attitude. In addition, patients have discovered that doctors are fallible in their assessments of what constitutes the patient's best interest. Thus, patients have demanded a greater degree of control over their medical care. In addition, more recent ethical codes have urged us to acknowledge that both research subjects and patients are autonomous persons deserving of

²³ Eric Cassell, "The Nature of Suffering and the Goals of Medicine", New England Journal of Medicine, (NEJM), 306, #11, p.640.

respect. Autonomy has emerged as the dominant principle in contemporary medical ethics. It has grown in importance as various groups, patients among them, have learned to insist on respect, and on the rights which they feel are their due, self-rule being chief among them.

In an historical context, it becomes easier to comprehend why medical ethicists today rely heavily on autonomy in their analyses. This concept has been the means by which patients and research subjects have asserted their dignity as persons able to make choices. But while the notion of autonomy has played a central role in the evolution of medical ethics, and while this role has been in large part positive, there is no guarantee that autonomy will prove useful in solving all questions in contemporary medical ethics. As we shall see in the following chapter, difficulties arise when we rely too greatly on autonomy in our dissection of medical dilemmas, especially those involving incompetent patients.

Chapter III: Autonomy Questioned

Autonomy played an invaluable role in the development of medical ethics in the last few decades. Its preeminence, however, has recently come under scrutiny, even by those who have been its most ardent supporters. First, not all definitions of autonomy are suitable for medical ethics. For one thing, autonomy in its most exaggerated form would leave patients unpleasantly isolated. Witness, for instance, Sartre's account of the conditions necessary for autonomy:

Man can will nothing unless he has first understood that he must count on no one but himself; that he is alone, abandoned on earth in the midst of his infinite responsibilities, without help, with no other aim than the one he sets himself, with no other destiny than the one he forges for himself on this earth.²⁴

Ethics would have won a strange victory indeed if it battled paternalism so that patients might feel "abandoned" and "without help." Sartre's definition is not what medical ethicists would describe as their goal for patients.

However, extreme ideas of autonomy, not unlike Sartre's, can filter into discussions of medical ethics. Daniel Callahan has pointed out a number of distorted and exaggerated notions of autonomy which he finds not in the philosophical literature but in common parlance, "in the streets." Callahan believes that these popular misuses can reveal weaknesses in a concept as it is

²⁴ Jean Paul Sartre, Being and Nothingness, Trans. by H. Barnes, New York, Washington Square Press, 1943.

transferred from the abstract into the real world. One such distortion of autonomy is the notion that "respect for the autonomy of others is sufficient ground for overriding my own conscience."²⁵ Like Sartre's definition, this version of autonomy would have damaging repercussions if acted upon by physicians.

But Callahan finds more that is disturbing about autonomy than that it can be abused. It is the lynch pin of medical ethics, yet it tells us nothing about many aspects of ethical conduct. For instance, autonomy cannot tell us how we are to conduct ourselves within a moral community. Bland recommendations not to interfere with the autonomy of other persons do not tell us how we are to respond to a call for help from a drowning man. Thus, Callahan fears that to put autonomy before all other values,

buys our freedom at too high a price. It establishes contractual relationships as the principal and highest form of relationships. It elevates isolation and separation as the necessary starting point of human commitments. It presumes that the moral life can be made a wholly voluntary matter..., thus attempting to deny the validity of many uninvited moral obligations that ordinary life with other people usually casts before us.²⁶

Thus autonomy, even in its purest form, cannot be the sole guide to ethical behavior. We must look further if we are to discern a basis for life with other people.

Callahan is not the only writer who has been a staunch

²⁵ Daniel Callahan, "Autonomy: A Moral Good, Not a Moral Obsession," Hastings Center Report, October, 1984, p.41.

²⁶ Ibid., p.41.

defender of autonomy, and yet who now feels that its location at the pinnacle of medical ethics must be re-examined. In "Autonomy's Temporary Triumph," Robert Veatch examines the ascendance of autonomy in its historical context. He believes that autonomy was necessarily granted paramount importance in order to create a "principle that responded to an extreme paternalism."²⁷ Paternalism may not be gone without a trace in practice, according to Veatch, but it has effectively been banished as a concept worthy of respect in the literature of medical ethics. Thus, Veatch feels that we may now turn our attention to tasks that lie ahead.

Like Callahan, Veatch finds wanting in autonomy a guide for relations in a community of ethical persons. Thus, he writes:

That autonomy trumped Hippocratic paternalism said nothing about the relation of autonomy to our duty to others to organize a community in a moral way. Thus, the goal has become one of recovering our sense of a moral community....²⁸

What Veatch tells us therefore, is that autonomy was a worthy first step in the construction of a more complete system of ethics. Autonomy guides relations between individual patients and doctors, but what is needed now is to graft onto this structure principles which will help us in larger social situations.

Veatch wants to go beyond the individual, who is both

²⁷ Robert M. Veatch, "Autonomy's Temporary Triumph," Hastings Center Report, October, 1984, p.38.

²⁸ Ibid., p.39.

guided and protected by autonomy, to include the community in an "ethic of justice." Autonomy will gradually take its rightful place among a host of values in this ethic of the future, and indeed will regain the lustre it has today only in those "rare cases" which concern an "isolated patient exercising his or her will unbounded by obligations to others."²⁹

Interestingly, Veatch never pauses to define the moral community he hopes to build. He does make passing reference to "an ethic of justice" which "affirms the equal status of individuals."³⁰ He does not mention any obligations felt by one equal individual toward another, nor does he discuss special protections for vulnerable persons. Although it is unfair to criticize Veatch's definition of community when he has not clearly presented it, the implication is that persons remain equal yet isolated when a community is founded upon autonomy.

As Veatch reflects upon autonomy's ascendance, and its now possible re-evaluation, he makes reference to that case which he feels most contributed to "autonomy's temporary triumph." Curiously enough, he cites the now famous case of Karen Quinlan, a young girl who lapsed into an irreversible coma. Karen's breathing was controlled by an artificial respirator, without which it was believed she would not survive. Her parents fought, against medical advice, to have this device removed. After protracted legal battles, Karen's father won the right to have

²⁹ Ibid., p.40.

³⁰ Ibid.

her respirator removed, so that she might be allowed to die. (Ironically, Miss Quinlan survived ten years after artificial respiration was discontinued.)

Veatch's discussion of Quinlan reveals a curious inconsistency. He tells us first that it is Quinlan whose case "established firmly and finally that there are limits on the physician's authority to do what he or she thinks will benefit the patient."³¹ While it is true that such limits were clarified by the Quinlan decision, I cannot share with Veatch the conclusion that Quinlan therefore offers proof that "autonomy trumped Hippocratic paternalism." Although paternalism has been dealt a blow, and rightly so, it is not at all clear that autonomy is the victor.

Since autonomy had proved fruitful in the struggle of research subjects and competent patients who desired respect, it is not surprising that Veatch would turn to this concept to solve Quinlan's dilemma. In this case, however, autonomy does not show us the path to respect.

I would not describe the legacy of Quinlan as the triumph of autonomy. Quinlan meant the end of a certain sort of autonomy for physicians, an autonomy which sometimes amounted to arrogance. Thus, paternalism was indeed trumped. However, the decision does not represent a victory for patient autonomy, for no patient could be less autonomous than Karen Quinlan.

The emphasis on autonomy seems cruelly misplaced as we

³¹ Ibid., p.39.

consider the plight of this wholly dependent young woman. There must be some other principle or quality we may call upon in order to demonstrate respect for a patient like Quinlan. We might invoke the "right to die," or alternatively the "right to life," but both these rights seem somehow hollow without an autonomous individual to claim one and forego the other. Karen's father believed that he was most qualified to determine both what was best for her, and what she would want. Thus, he invokes the right of parents to make decisions for their dependent children. And yet that right is curtailed by the doctrine of parens patriae -- the duty of the state to protect vulnerable persons, including children whose parents may make harmful decisions for them.

We might invoke a number of other rights, but each is flawed in precisely the same way; they seem to draw attention away from where it belongs, on Karen Quinlan, the dependent patient, who is incapable of exercising any right.

It is possible to describe the dilemma of Quinlan in a way that does not focus on autonomy or on any other right. We may view the situation as one involving various persons, each acting in good faith, and each attempting to express a different idea of what will benefit Karen. Karen is also an actor in a sense, in that her presence forms a cry for help. Her plight demands that we act upon those responsibilities we feel as members of a moral community.

Karen's family acts within the relationship of love; they want an end to her suffering. Her physicians, we assume, act

upon their sense of professional duty. They do not want to abandon their patient; they would like to do everything medically possible for her. This conflict is not essentially one of autonomy versus paternalism; it is between various persons who feel an obligation to help someone who is dependent upon them, a theme we will develop in subsequent chapters.

Thus, I disagree with Veatch, who says autonomy should be our first principle in cases like that of Quinlan, and that we must add lesser principles to it as we include the concerns of the community. I believe that we should be able to devise one set of principles which show us how to respect both autonomous and non-autonomous patients. As it is, we have a system which tells us nothing about how autonomous persons behave within communities. Even worse, this emphasis on autonomy seems to deny the very existence of an incompetent patient like Quinlan. We cannot simultaneously respect the patient and ignore the conditions of her existence. The failure of autonomy is upon us, for we are already in our community, which is comprised of both autonomous and dependent persons, and sorely in need of an ethics to guide us.

Chapter IV: Theories of Moral Development

Kohlberg's Stages

Often, studies from another discipline may shed light on one's own endeavors. In the present case, psychological studies of moral development may help us in our examination of medical ethics. Psychologist Lawrence Kohlberg has described moral development as striving toward an ethics of rights. As in the legal system, he places autonomy, guided by reason, before all other principles. His work has been usefully criticized by his former student, Carol Gilligan. The flaws she finds in Kohlberg's system will direct us as we examine medical ethics with its current emphasis on autonomy.

Kohlberg greatly advanced the study of moral development. He believed that development occurs by way of a set of irreversible and invariant stages. As children's cognitive capacities mature, so too do their capacities for moral reasoning. Thus, Kohlberg felt that moral reasoning did not merely change with age, but improved. Further, these improvements were linked to a child's ability to grasp a set of hierarchical moral principles, beginning with the most primitive and working up to the most sophisticated. Thus, if a child reasoned at level two of Kohlberg's six stages, he would almost certainly not be able to understand reasoning at level five or six. The reverse, however, would not be true; children

reasoning at level five would have passed through level two and would thus be able to comprehend its underlying principles.

Kohlberg believed that these principles were universal to all cultures and all eras. Although he found that the majority of adults in some cultures reasoned at a "lower" level than those of other cultures, he attributed this difference not to a bias in the theory nor to inherent inferiority of the less advanced cultures, but to a poverty of environment that left those groups unexposed to more advanced forms of moral reasoning. Those cultures which seemed to lag behind by Kohlberg's measures tended to be rural and non-Western.³²

Kohlberg's basic method was simple yet elegant. He presented the volunteer with a hypothetical moral dilemma. This person was asked how he would solve the problem, and why. The Heinz dilemma was the one most frequently used. In this story, Heinz's wife suffers from a deadly disease. A drug exists which can save her life, but the druggist will only sell it for two thousand dollars in cash. Heinz is a poor man with no access to such a sum. The volunteer must decide what Heinz should do, and explain the reasons. These reasons, and the moral maturity they reflect, determine one's level in the Kohlberg system.

A detailed examination of Kohlberg's stages is beyond the scope of this work; we will describe the stages briefly, and comment on those principles which are relevant.

³² Lawrence Kohlberg, The Philosophy of Moral Development, San Francisco, Harper and Row, 1971, chapters 2-5.

Kohlberg's theory posits three levels which are broken up into six stages. The preconventional level is the least advanced, and contains stages one and two. Persons who operate at level one are concerned with obeying rules in order to avoid punishment. At level two, persons act to further their own self-interest.

The next level up in Kohlberg's hierarchy is the conventional level. Persons at stage three, "the stage of mutual interpersonal expectations," are concerned with "keeping mutual relationships, maintaining trust, loyalty, respect, and gratitude." Motivation centers on the need to be perceived as good in one's own eyes and in the eyes of others.³³ Stage four, also within the conventional level, is characterized by the desire to fulfill obligations to which one has agreed, in order that society and its institutions may be maintained; this stage has been dubbed the "law and order mentality."

The postconventional level begins with stage five, in which the right is upholding the basic values of a group, even when those values conflict with actual laws of the group. One upholds these values because of a felt obligation to protect one's own rights and those of others. Just like pledges to uphold the law, "Family, friendship, trust and work obligations are also commitments or contracts freely entered into...."³⁴

For a person who has reached stage six, moral behavior is

³³ Kohlberg, 1981, p.411.

³⁴ Ibid., p.412.

"guided by universal ethical principles. Particular laws are... valid because they rest on such principles." One behaves this way because, "as a rational person, one has seen the validity of principles and has become committed to them." This highest stage is consistent with Kant's vision of an autonomous will guided solely by reason.

Thus, concentrating on stages three through six, Kohlberg depicts a line of development which moves from "mutual interpersonal expectations," to a drive to maintain social systems, to a stage where relations are viewed as contractual. The highest stage derives from a Kantian social perspective of a "rational individual recognizing the nature of morality or the basic moral premise of respect for other persons as ends, not means."³⁵

Kohlberg's hierarchy of principles is like current medical ethics, for both award the greatest respect to the Kantian principle of autonomy. Both systems are consistent with the ethics of rights. In addition, Kohlberg explicitly describes the desire to maintain relationships because of human feeling as a less advanced principle, to be surpassed by learning to see relationships as essentially contractual.

Gilligan's Critique

In the early 1970's, Carol Gilligan, hoping to study the reasoning of persons in actual, as opposed to hypothetical, moral

³⁵ Ibid.

dilemmas, cast about for an appropriate research topic. Gilligan chose to study pregnant women who were considering abortions. The women discussed their own real dilemma, and also reflected upon hypothetical cases, such as the Heinz dilemma. Her method thus differed from that of Kohlberg, who used only hypothetical dilemmas. Gilligan noticed that when women's responses were graded according to Kohlberg's stages, few women passed the level of conventional reasoning, as compared to men of similar age and educational background. Gilligan also drew attention to the fact that all the subjects in Kohlberg's original study, from which he derived his stages, were male.

These observations could be explained in a number of different ways. Kohlberg, like his predecessors in psychology, believed that women were in fact limited in their moral development. He hoped, though, that as they moved beyond the domestic sphere and into the professions, the more complex moral dilemmas they encountered would stimulate their development to stages five and six.³⁶

Gilligan preferred a different explanation. She suggested that women's moral reasoning is neither stunted nor developmentally delayed, as had been suggested by Freud and Piaget before Kohlberg, but that it honors principles neglected in systems like that of Kohlberg. We will describe the moral principles elicited by Gilligan as an ethics of responsibility,

³⁶ Lawrence Kohlberg and R. Kramer, "Continuities and Discontinuities in Childhood and Adult Moral Development," Human Development, 1969, Vol. 12, pp.93-120.

or of care. The ethics described by Kohlberg we will refer to as the ethics of justice, or of rights.

A Different Developmental Sequence

According to Gilligan, what Kohlberg has described is one possible sequence of moral development, but one that does not apply to the women in the abortion study. Gilligan proposes that the moral development of these women follows a different sequence, which she sets out to describe. This sequence includes three stages, and these are demarcated by two transitional phases.

The first and most primitive of these three stages is characterized by the quest for personal survival. A person in stage one cares only for the self, and sees the needs of others exclusively in terms of self-interest. An example of such logic is provided by one of the participants in the abortion study, in response to the Heinz dilemma:

Stealing might be wrong, but if you have to do it to survive yourself or even kill, that is what you should do....Preservation of oneself, I think, is the most important thing. It comes before anything else in life.³⁷

This first phase recedes as one begins to realize that the exclusive pursuit of personal survival is selfish; the emergence of such self-criticism marks the first transition. A person whose reasoning attains the second phase eschews the selfishness

³⁷ Carol Gilligan, In a Different Voice: Psychological Theory and Women's Development, Cambridge, Harvard University Press, 1982, p.76.

of the past, and seeks instead for a new sense of responsibility and social participation. This new phase is not without deficiencies, however, for in it the needs of others are placed above those of the self, and self-sacrifice stands as the moral ideal. Moral choice at this stage closely resembles that assigned to the stereotype of the all-loving, all-giving mother. Gilligan offers a number of examples of this "feminine identification of goodness with self-sacrifice."³⁸ One woman, in deciding whether or not to abort, discussed her responsibilities not only toward the fetus and her unsupportive lover, but also toward his wife and children, without giving equivalent consideration to her own needs. Another young woman described her inability to criticize thus: "I never want to hurt anyone, and I tell them in a nice way, and I have respect for their opinions, and they can do the things they want."³⁹ Concealed within this "niceness" is a passivity, a willingness to let others act and to attribute one's own actions to another's demands or needs.

Although this level of reasoning betrays some philosophic inconsistency, it also reveals some positive attributes within the ethics of care. Already displayed are the desire to avoid hurting others, even if this should entail bending the rules of justice. Also visible is the goal of maintaining relationships between the parties in a dispute, even though it may require, at

³⁸ Ibid., p.80.

³⁹ Ibid.

this stage, a sacrifice of personal aims.

The second transition commences when the individual realizes that violence is done to the self by a too exclusive concern for the needs of others. The passivity of the second phase comes into question, and these women face clearly and honestly their identity as the maker of moral choices. They take responsibility for decisions and their consequences. Thus, in the third phase, one strives to incorporate the self into that community which is deserving of non-violent treatment; there is a balance of care for self and other.

Throughout her book, Gilligan argues that progress in moral reasoning is linked to progress in self-concept; women whose reasoning attains the third level persistently refer to this link, offering evidence for Gilligan's contention. For example, one woman describes herself in the past thus:

Usually paying off some sort of debt, going around serving people who are not really worthy of my attention, because somewhere in life I got the impression that my needs are really secondary to other people's, and that if I...make any demands on other people to fulfill my needs, I'd feel guilty for it and submerge my own in favor of other people's, which backfires on me, and I feel a great deal of resentment for other people....⁴⁰

Having reflected on the errors of these past perceptions, the same woman goes on to describe her current ideas of responsibility:

I have this responsibility to myself, and you know, for once I am beginning to realize that that really matters to me. Instead of doing what I want for myself and feeling guilty over how selfish I am, you realize that that is a very usual

⁴⁰ Ibid., pp.92-3.

way for people to live....⁴¹

This woman comes to accept her needs as equivalent in weight to those of the people she loves. Her stance is neither excessively selfish nor self-sacrificing.

In summary, Gilligan's sequence moves from selfishness toward a sense of responsibility for others instead of for the self. From this emphasis on self-sacrifice, one moves to the view that self and other are interdependent, and that both deserve attention within the ethics of care. Although Gilligan describes this third phase as the highest within her system, she suggests that even greater maturity and moral insight are reached by those who blend her system with Kohlberg's, taking into consideration both the ethics of responsibility and of rights.

Distinguishing Features: Maintaining Relations

Apart from a different set of stages, this new orientation has several characteristics which distinguish it from Kohlberg's system. Chief among these differences is the emphasis on maintaining relations among disputing parties. Indeed, it is this feature which provides the springboard for Gilligan's attack on Kohlberg. In Kohlberg's system, such social concern causes a response to be ranked as stage three out of six, i.e., one guided by conventional rather than principled reasoning. However, this concern is central to so many of the female participants in Gilligan's abortion study that the vast majority of their

⁴¹ Ibid., p.94.

responses are categorized as conventional. It is women's concern for maintaining relations that is considered in Kohlberg's system as "immature." The core of Gilligan's argument is that this concern is mature and appropriate; that it has been deemed otherwise is the result of a persistent, long-standing distortion in psychological theory. Gilligan indicts not only Kohlberg for the work that causes women's responses to seem deficient; she also criticizes such renowned figures as Freud, Piaget and Erikson. It is, in part, this wide-ranging nature of her critique that garnered for Gilligan's book so much attention, both favorable and unfavorable.

Gilligan argues that earlier writers have singled out such values as independence and detachment as goals of maturity, and have undervalued interdependence and attachment. If psychological development has traditionally been viewed as a struggle for ever more independence, moral development has appeared in an analogous fashion, as a struggle for increasing intellectual detachment and autonomy. Such a view is consistent with the ethics described by Kohlberg, with its rule-oriented approach to moral reasoning. Gilligan argues that this over-emphasis on detachment is not only inaccurate, in that it does not describe the development of women, but also that it is philosophically inadequate, in that it denies the importance of attachment in morality.

In more recent work, Gilligan has considered the origins of both the care and justice orientations in moral reasoning. She

theorizes that both "voices" arise from certain profound childhood experiences. One such experience is that of inequality, the child's "awareness of being smaller and less capable than adults and older children."⁴² From this experience, Gilligan argues, psychologists have learned to define morality as justice, and development as progress toward equality and independence.

However, Gilligan notes, the experience of attachment is as prevalent and as critical as that of inequality in shaping children's notions of right and wrong, and it is from this experience that the care orientation derives. She finds that the majority of women and men, when asked to resolve moral conflicts, will introduce both justice and care concerns, but will focus their reasoning on one orientation or the other. Women who focus tend to do so almost equally in either category, while men who focus do so almost exclusively in the justice orientation. Gilligan's work has been quite controversial, particularly as it relates to sex differences. A careful reading of her work, particularly the more recent studies, reveals that her concern is not simply about the devaluation of women's moral judgments; she also defends men who reason within the ethics of care. Rather, she decries the notion that attachment is unworthy to affect moral questions. Gilligan does not insist that women always reason one way and men another, but that there are two moral viewpoints that deserve to be heard respectfully.

⁴² Carol Gilligan and Grant Wiggins, "The Origins of Morality in Early Childhood Relationships," unpublished draft, November, 1985, p.5.

Gilligan uses two opposites of the word "dependence" to reveal salient differences in the two systems:

These contrasting opposites of dependence -- independence and isolation -- illuminate the shift in the valence of relationships that occurs when connection with others is experienced as impeding autonomy and when it is experienced as protecting against isolation.⁴³

One's ideas about attachment alter notions about whether detachment is good or bad. From this example we learn much about how Gilligan views the two moral orientations. Neither care nor justice provides a "better" way of seeing, but each does provide a vastly different viewpoint; so different, in fact, that each orientation seems to require a different language. Thus, a concept like dependence may have a radically different meaning, and may be subject to either praise or blame, according to one's point of view. The lessons of one orientation may be inaudible to those who speak the language of the other.

In addition to providing insight about how misunderstandings arise, Gilligan's example of the contrasting opposites of dependence reveals some of her reservations about standard notions of moral maturity. By inviting the concept of attachment into the moral domain, Gilligan causes us to re-examine traditional concepts. She challenges the notion that detachment is essential for mature moral judgment, and asks us instead to imagine circumstances when detachment can prevent moral reasoning

⁴³ Carol Gilligan, "Remapping the Moral Domain: New Images of the Self in Relationship," in Reconstructing Individualism, ed. by Ian Watt; Palo Alto, California, Stanford University Press, 1986, p.251-2.

from reaching its full potential. Thus, "the seemingly valuable capacity to resist impulses toward domination and treat self and other with equal respect can be seen as the problematic ability to resist moral feeling and turn away from need."⁴⁴ We shall return to this problem when we discuss the concept of emotional neutrality in the legal system, in chapter V.

For Gilligan, the link between morality and relation is not part of a phase to be outgrown, but is the necessary context for moral choice. The recognition of attachment, also known as love, is the central difference between the systems of Gilligan and Kohlberg. Indeed, this concept is of such singular importance in Gilligan's model that all other distinguishing features follow from it. We shall investigate further the interaction of attachment and morality in chapter VI, when we examine Iris Murdoch's work.

Rules and Their Role

Piaget observed that boys and girls at play evinced notably different ideas about how and when rules ought to be used. Gilligan builds on this work to describe how rules are perceived within the ethics of care. Piaget noted a certain zest in boys for the elaboration of rules, and of procedures for settling conflicts, while girls exhibited a "tolerant attitude toward rules."⁴⁵

⁴⁴ Gilligan, "Origins of Morality," p.25.

⁴⁵ Gilligan, Different Voice, p.10.

More recent work has tended to corroborate Piaget's observations. When psychologist Janet Lever studied children's games, she found that when faced with conflict, girls tend to end the game rather than fight. Boys, on the other hand, seem to view the analysis and adjudication of conflict as an integral part of the game.⁴⁶ In the flexible attitude displayed by girls toward rules, we can see the force of their notion of attachment. The game and its rules are not worth as much as the maintenance of peaceful relations. This attitude has in the past been part of what has caused Freud and other writers to find in women a poorly formed moral sense. Gilligan contests this, arguing that in certain circumstances, moral maturity may lie precisely in the ability to value relationships over rules.

Specific Cases

During her work on abortion decisions and in subsequent research, Gilligan noted more frequently in girls and women an eagerness to know the particulars of a situation; they seemed dissatisfied with the information provided in hypothetical dilemmas. For instance, in responding to the Heinz dilemma, girls persistently asked for additional information about the involved parties. Was Heinz a poor man, or a member of an oppressed minority? Was he likely to be treated fairly in court? The implication, and often the explicit justification for this curiosity, is that details make a difference. The particulars of

⁴⁶ Quoted in Gilligan, Different Voice, p.9.

a dispute, including the identities and circumstances of the people involved, matter enormously in terms of designing a morally correct solution. Gilligan's volunteers are not the only ones dissatisfied with hypotheticals. Male, as well as female, medical students will often press for details, without which they feel the case cannot be resolved, when presented with hypothetical moral dilemmas.⁴⁷ Hence, rules in the abstract do not always provide adequate guidance. The flaws of blind justice are discussed more fully in the following chapter.

The implication is that those who reason within the care orientation, as the girls and women did, are unwilling to make certain basic assumptions in order to "solve" the Heinz dilemma. One such assumption is that the disputing parties are equal; each party has equal freedom of choice, and equal power to act upon their decisions. This emphasis on equality fits in well with the moral community hinted at by Veatch. By contrast, care-oriented reasoners do not assume equality, but instead suspect that inequalities exist, and that they will radically alter the nature of the "right" solution. Their desire to balance inequities of power and need causes these women discomfort in responding to hypothetical dilemmas. This difference in approach is one result of the shift from an ethics of rights to one of responsibilities.

Uncertainty

If women tend to demote rules as generating inadequate

⁴⁷ Robert Levine, personal communication.

solutions, it is not because they find greater certainty in another method. Indeed, many responders attribute their skepticism about rules to their belief that moral dilemmas can not be resolved with perfect clarity. Clarity itself becomes suspect, for fear that such certainty has been purchased by neglecting some subtle yet vital aspect of the situation. In her essay, "On Morality," Joan Didion reflects a profound distrust of moral certainty:

There is some sinister hysteria in the air out here tonight, some hint of the monstrous perversion to which any human idea can come. 'I followed my conscience.' 'I did what I thought was best.' How many madmen have said it and meant it? How many murderers?...Maybe we have all said it, and maybe we have been wrong. Except on the most primitive level -- our loyalties to those we love -- what could be more arrogant than to claim the primacy of personal conscience?⁴⁸

Didion equates certainty with a "monstrous" arrogance, except when it occurs in the context of attachment.

Gilligan's responders echo this mistrust of certainty, based on their conviction that there is always another way of looking at a situation. In noting that their system of moral reasoning "leaves them with conflict," these women do not see the lack of clarity as a flaw in the system, but as an inevitable problem in making moral choices. What certainty there is, is revealed through attachment. Here the responsibility-centered reasoners differ from their rights-centered counterparts, who feel that by correctly applying the right principles in a detached fashion,

⁴⁸ Joan Didion, "On Morality," Slouching Toward Bethlehem, New York, Washington Square Books, 1968, p.161.

the right solution can be unequivocally determined. One ought to avoid the influence of personal feelings. For example, one much quoted adolescent boy, reasoning within the ethics of rights, stated that the Heinz dilemma is "like a math problem with humans."⁴⁹

Why is it that the shift of emphasis from rights to responsibilities should lead to the acceptance of uncertainty? The answer, at least in part, lies in the belief that "right" answers are determined not by a permanent hierarchy of principles, which guide conduct among rational equals, but by a shifting network of inequities. The "right" answer in a dispute among equals might not serve at all when one person is more vulnerable, or otherwise more in need of protection.

There are, however, other plausible explanations for the uncertainty so prevalent among care-oriented reasoners. One is that the women who predominantly make up Gilligan's sample do not find their style of reasoning supported by society as a whole. The experience of being told repeatedly that their concerns are not moral concerns, and that their reservations about hypothetical dilemmas are not valid, causes them to doubt their own judgments. Their experience is not unlike that of some doctors, whose reasoning focusses on the care of patients, yet whose decisions are judged within the ethics of rights to be inconsistent or irrelevant.

Although Gilligan attributes part of the blame for this

⁴⁹ Gilligan, Different Voice, p.26.

uncertainty to society's justice-oriented bias, she also finds the care orientation itself to be partly at fault. Gilligan offers numerous examples of women who lose sight of their own point of view by their very ability to take into account the viewpoints of so many others. Consider, for instance, the young woman who accepted an abortion she did not want because of her perceived responsibilities toward the wife and children of her unsupportive lover.

In the end, Gilligan finds uncertainty to be an inherent, but not necessarily an admirable feature of the care orientation. It is, perhaps, a flaw which balances an equivalent error in the justice orientation. She relates her view thus:

If the persistent error in care reasoning is vacillation and lack of clear judgment, resulting from a tendency to include all possible ways of seeing, the persistent danger in the justice-reasoner is moral arrogance, the irrational faith in the infallibility of judgments from principles rigidly applied to a situation.⁵⁰

Gilligan does not view the care orientation as superior to the justice orientation, but as a counterpart to it. The goal is not to substitute one orientation for the other, but to incorporate the lessons of each into an approach that corresponds to the complexity of human dilemmas.

In summary, Gilligan offers us a new context in which to consider moral development and moral choice. This orientation favors attachment over detachment, and this increased emphasis on relation causes a shift in the value of other attributes. As we

⁵⁰ Gilligan, "Origins," p.34.

turn our gaze to the legal system, we will question its assumptions in much the same way that Gilligan has challenged Kohlberg.

Chapter V: Implications for Medical Ethics

No Contest

Before distinguishing further the ethics of rights from the ethics of responsibility, let me set to rest one misconception: the ethics of rights is not a "bad" system exclusively favored by lawyers, in contrast to a "good" system favored by doctors. The ethics of rights is the mainstream voice of moral reasoning in our society. Kohlberg did not set out to describe the moral reasoning of lawyers, but of people in general. Gilligan did not set out to correct legal thought, but to argue that moral reasoning ought rightly to include an acknowledgment of the interdependence of human beings. The flaw in reasoning about proxy decisions cannot be simply ascribed to lawyers; nor is the solution to exclude legal intervention. The flaw is as much in the medical profession for not having learned to fashion decisions that are consistent and clear, and yet which incorporate the weight of subjective and emotional knowledge.

Arguments persistently erupt about whether doctors or lawyers ought to make decisions about withdrawing life-sustaining treatments. Although doctors have long been involved in helping families through such decisions, it is not clear that they are well trained to do so, or that they are experts in this area. Although bonds exist between patients, doctors and families that establish the basis from which responsible decisions spring, this

relation does not in and of itself guarantee good decisions. For these, one needs excellent communication and clear thinking to help families sort out the various technical, ethical and emotional dimensions of the dilemma. Not all doctors possess these qualities.

Many lawyers believe these decisions are properly legal ones. George Annas strongly defends the adversary process as the best means for airing the viewpoints of all interested parties, and thus arriving at a disinterested version of the facts.

However, Annas also states:

Judges are asked to decide this question not because they have any special expertise, but because only they can provide the physicians with civil and criminal immunity for their actions. In seeking this immunity, legal considerations quickly transcend ethical and medical judgments.⁵¹

Annas, staunch defender of legal intervention, admits that courts are not asked to intervene because of concern for the patient. The legal expertise demanded focuses on the threat of punishment to others, and thus represents a shunting away of attention from the vulnerable patient -- a theme we shall return to later in the chapter. Although Annas believes that the courts nonetheless produce good decisions, it is not because of specifically legal expertise, but because the courts extend their mandate to include ethical issues.

Thus, both law and medicine reach beyond technical expertise

⁵¹ George Annas, "The Incompetent's Right to Die: The Case of Joseph Saikewicz," Hastings Center Report, February, 1978, p.21.

in grappling with issues of life-sustaining treatment. In general, because of their direct observation of the patient, doctors and families are well situated to determine which measures are benefits or burdens, and thus to approach the ethical dilemma with relevant data. For this reason, most proxy decisions are made without legal intervention. However, it is not possible to entirely escape legal supervision, for there will always be cases in which doctors and families cannot agree. In accord with the President's Commission, I feel that there are many fewer genuinely difficult cases than are commonly expected.⁵² By relying on the ethics of responsibility, and so creating clear, principled, humane decisions, we should be able to drastically reduce the need for judicial intervention.

The enormous effort expended on procedural matters, such as who should decide, distracts us from the task of deciding what should be done. When physicians and courts have decided well, they have bent the traditional rules of analysis, and have included subjective and emotional factors. They have not always been clear, however, that this is what they are doing. And when poor decisions have been made, ones which uphold the rights but not the needs of the vulnerable patient, it is not always the fault of the courts. Indeed, in the case we shall examine most closely, that of John Storar, the courts sided with the physicians and against the family, to the detriment of the

⁵² President's Commission, Deciding to Forego Life-Sustaining Treatment, Preface.

patient.

As we discuss the ethics of care, some physicians may feel that these concepts are not entirely new, and they would be correct. The ethics of responsibility borrows from the Hippocratic tradition its insistence on care, while leaving behind the image of the doctor as sole decision-maker. The ethics of responsibility incorporates notions that match an old-fashioned ideal of the physician as an empathetic person who fought for cure yet never neglected to comfort the dying. The new-found ability to cure, or at least to intervene, leads us to denigrate this ancient duty. Dying patients do not represent our failures. Yet sometimes they appear to, and so our best efforts are expended in devising ways and reasons to treat. Although we should continue to seek cure where possible, we ought also to devote more energy to the care of the dying.

The ethics of rights and of responsibility are not mutually exclusive. One need not reject the concept of rights in order to accept the ethics of responsibility. Rather, this new ethics is an attempt to incorporate concepts which are central to medical decision-making, yet which are difficult to express within the rights model.

Although physicians, families and lawyers have all had occasion for dissatisfaction with legal remedies, most participants are willing to accept the system's flaws because they believe no reasonable alternative exists. The flaws of rights-based ethics in resolving medical dilemmas do not

represent necessary evils, however, but reveal instead that the legal context is fundamentally ill-suited to solving such dilemmas.

By using Gilligan's ideas about relationship and responsibility as a point of departure, we can fashion a framework for resolving medical dilemmas -- an ethics of care -- which improves on the current legal model.

Rights in Action

Let us begin by examining rights-based ethics in action, i.e., in the courts. Each of the disputing parties hires a representative who presents the case as favorably as possible for his or her client. Generally, clients cease to communicate directly with each other, but interact only with their lawyers. The lawyers communicate less with each other than with the judge. In short, a series of barriers to communication is interposed between the disputants. The presentations of the two lawyers are evaluated by a judge, who is ideally neutral, and who will decide which representation is correct. Thus, essential features of a court case are the adversarial positions of the two disputing parties, the exchange of direct communication for third party communication, and the presence of a neutral observer, the judge, in whom rests the final authority.

Two sets of objections may be raised against this theoretical description of the legal process. One is empirical: things don't work that way. The other is moral: we ought not to

do it that way. Let us address the empirical question first, and ask in what ways this picture is factually inaccurate.

The question of judges' impartiality, specifically as it operates within medical dilemmas, has been addressed by Robert Burt in his interesting book, Taking Care of Strangers.⁵³ Burt attacks the concept of the "choiceless self-conception," the notion that judges are mere conduits of justice. According to this idea, judges apply rules of law in a way that is not influenced by personal or emotional concerns. The judge is not an "I" who wrestles with issues as only he can, and decides for reasons that are unique to him as an individual. Rather, the judge is a very advanced sort of computer who dissects the case into its component parts, and analyses these according to rules which are, theoretically, publicly knowable. The judge then spews out an answer -- the same answer that any other properly functioning computer would give. In this way the judge is "choiceless;" he is merely a location where there occurs a rational, theoretically repeatable process. This definition of the judge's role conforms to the concept of "legalism," as described by philosophers John Ladd and Judith Shklar. To them, legalism means, "the ethical attitude that holds moral conduct to be a matter of rule following, and moral relationships to consist of duties and rights determined by rules."⁵⁴

⁵³ Robert Burt, Taking Care of Strangers, New York, The Free Press, 1979.

⁵⁴ John Ladd, "Legalism and Medical Ethics," Journal of Medicine and Philosophy, 3 (March, 1979), p.4.

This "choiceless" judge, who is utterly rational and detached, is most at home in the ethics of justice, as described by Kohlberg. There is one right answer, which can be discovered with certainty by the process of reason. But this definition of the moral agent does not correspond to reality, as it exists in the courts.

Burt notes that the concept of choicelessness was attacked as long ago as the 1930's by the "legal realists." However, he also points out that those authors failed to see the "seductive power" of this choiceless self-conception.⁵⁵ Interestingly, Burt attributes the allure of the concept to the judge's desire to escape the painful burden of responsibility.

Burt suggests that judges are not impartial, especially in cases of life and death. They maintain a pose that they are conduits of justice, and that they are unmoved by the impact of their decision on the life of the patient. The pose of neutrality is, however, a fiction. The very act of analyzing a case, and deciding which issues need concern us, and which do not, sets the case in a certain light. Such decisions are not made, according to Burt, on a purely rational basis. Neither is it true that if the facts are clear, the right decision follows obviously from them. In the medical dilemmas which concern us, the problem is one of moral choice. There may be factual issues to decide (can this patient feel pain?) but the greatest difficulties arise in deciding the moral aspect of the case (is

⁵⁵ Burt, p.19.

it right to terminate life support systems for a patient who feels, or does not feel, pain?). The emotional neutrality of judges may be compromised in any type of case, but is particularly at risk in medical cases.

While judges cannot escape the impact of emotion, its effect is far greater on the patient's family members and physician, who are attached to the patient by special relationships that make emotional neutrality an impossibility. And here is where the moral objection to legalism arises -- we should not aspire to the impartiality the law requires. It is by acknowledging connection, not denying it, that we make appropriate moral decisions.

The Legal Battle

An essential aspect of the legal system is its adversarial nature. How does this opposition function in relation to medical dilemmas? Again, we are confronted by the sensation of an improper fit between legalism and the task of making decisions for incompetent patients. First of all, the relationship between doctors and families is not inherently an adversarial one. Indeed, it must at one time have been otherwise or there would be no such relationship. The entrance into the legal system, however, lends official status to whatever pre-existing hostilities there might have been.

If we return to the moment where the family and patient first make contact with the doctor, we find that, far from being

adversaries, all are united by their common responsibility for the patient's welfare. Thus, these various parties, though they disagree, are not fundamentally opposed to one another, for no matter how bitterly they may dispute the methods, they work toward a common goal.

One might argue -- with some justice -- that it is unfair to blame the legal system for all animosity between disputing parties. Considerable tension must exist before a medical question arrives in a court of law. However, the experience in court is unlikely to dissipate existing tensions. On the contrary, any revival of trust becomes increasingly unlikely because the disputants have little direct communication, while the lawyers depict the actions of the opposition in the most unfavorable light possible. As a result, one good outcome -- the restoration of cordial relations between family and doctor -- becomes a virtual impossibility before we even begin to resolve the medical dilemma. Thus, the imposition of the legal system onto medical dilemmas injects an adversarial note which is neither fundamental to them, nor helpful in crafting a responsible resolution of them. The severance of relations and trust which accompany the conclusion of this sort of medical dispute is not a legal success, but a medical tragedy: the network of persons jointly concerned for the patient's welfare is destroyed.

Hostility is not simply a part of the legal process; it is essential to the very concept of rights. As Ladd argues:

To have a right is to have a right against someone...The natural and normal situation in which one asserts a right occurs when the person against whom it is asserted threatens, neglects, or otherwise appears unwilling to accede to one's requests, needs, or demands... In sum, the concept of rights is most characteristically invoked in an adversary context.⁵⁶

The standard position of participants in the legal system is to accept the adversarial nature of law as a necessary evil. For one thing, it is thought to be an efficient means of uncovering truth; the lawyers, who defend their clients as aggressively as possible, are tireless in their efforts to unearth unflattering data about the opposing side. Robert Burt presents an unusual form of this argument. He discusses the imbalances of power among various parties, including the judge and the incompetent patient. He claims that the adversarial process is helpful in protecting the patient from being "overpowered" in legal proceedings, because families and doctors are more likely to consider the patient's needs if they fear legal punishment for improper decisions.⁵⁷ Burt also indicates that if families and doctors learn to respect patients as they ought, the result will be fewer decisions to terminate treatment. His contention is based on an inappropriate definition of respect, which we shall discuss in the following chapter.

Contrary to what Burt suggests, I feel that the threat of punishment is more likely to prevent appropriate decision-making than to encourage it. Communication will hardly be fostered in

⁵⁶ Ladd, p.17.

⁵⁷ Burt, p.168.

such an atmosphere, yet it is sorely needed if all parties are to discuss their responsibilities and concerns for the patient. Indeed, the fear of reprisals serves to remove concern for the patient from center stage, and place there instead concern for one's own survival, as well as excessive worry for how an anonymous third party might view this decision from the outside.

Sartre describes such a situation by asking us to imagine that someone catches us in the act of looking through a keyhole. Even if we are doing this because someone in the room has asked us to do so, in order to know what can be seen through the keyhole, we are made to feel guilt or shame because of the "suspicious stare of the Other."⁵⁸ Similarly, physicians and families who know their actions could be evaluated in court, experience a shift in their own view of the decision-making process. This threatening influence leads to more concern about how things look, than about how they are.

Burt accepts the threat of punishment as necessary to ensure that adequate attention is paid to the decision-making process. The adversarial nature of the justice system serves as a harsh sort of study aid, much like the hickory stick of the one-room school house. But we need to ask ourselves if such attention -- by force -- is well-suited to making the kinds of moral choices that participants face.

Burt sidesteps this issue; I would like to examine it

⁵⁸ Jean-Paul Sartre, Being and Nothingness, Translated by H. Barnes, New York: Washington Square Press, 1966.

directly. It is possible to describe moral choice -- outside of the ethics of rights -- in such a way that emotion and attention are organic parts of the decision-making process. Threats are not required, for attention is already riveted by the nature of the responsibility of choice.

Burt recognizes that emotionality enters into these decisions, yet he remains within the adversary system. The level of debate is thereby reduced to moral choice at what Kohlberg and Gilligan would agree is an extremely primitive level. It is as if moral choice falls into neat halves. It is either all of one thing or all of another; it is entirely rational or entirely irrational, i.e., emotional. Relations among persons are similarly dichotomous; either they are paternalistic, in the sense of one party being overpowered by the other, or they are individualistic, in the sense of both parties being wholly free and unrelated to each other.

Caroline Whitbeck refers to this kind of attitude as "dualism," which she finds throughout the ethics of rights.⁵⁹ Whitbeck correctly argues that the dualist approach is not our only alternative. It is possible to construct a system which is not fundamentally adversarial, and in which attachment and reason do not stand as opposites. In such a system, relations among persons need be neither paternalistic nor atomistic. This shift

⁵⁹ Caroline Whitbeck, "A Different Reality: A Feminist Ontology," in Beyond Domination: New Perspectives on Women and Philosophy, ed. by Carol Gould, Totowa, New Jersey, Rowman and Allanheld, 1983.

in the nature of relation changes the nature of moral choice.

Varieties of Attachment

An examination of relationship is crucial to our understanding of the ethics of responsibility. Let us first examine the relation of doctor and patient. We will draw a picture in which emotion is notably lacking, and then ask how this image differs from reality.

In this extreme example, the doctor is viewed as a business consultant. The patient, in managing his health, becomes aware of a problem, yet lacks relevant information. He or she then asks the doctor to gather and analyze data, and to provide a set of alternative solutions. Thus informed, the patient selects one of these options. As in any other business decision, considerations such as cost, convenience, and risk are factored into the equation.

There are a number of flaws with this picture of the doctor's role. From an empirical point of view, it is not possible to achieve such a perfect sharing of information between doctor and patient. The doctor's years of experience in relevantly similar cases may lead him or her to believe that in this particular case, one option surpasses the others, for reasons that may prove impossible to fully express. In addition, it would be surprising (and inadvisable) in serious matters for a doctor to have no preference for one treatment over another. And having such a preference, the doctor would no doubt communicate

it, however subtly. In the majority of cases, therefore, it would be impossible for doctors to present neutrally a list of options for the patient to consider. The doctor can not entirely avoid the burden of authority, but will to some degree maintain the advantage in terms of information; the patient must to that extent trust the doctor.

This matter of trust is interesting, for it has distinctly emotional connotations. And if the relation between doctors and patients is emotional in this respect, might it not be in others as well? Indeed, a host of powerful, although often unspoken emotions spring up between doctor and patient. To ignore these emotions, or to argue that they ought not to occur, is to belie the fact that they do in fact exist, and that they exert an impact on the way medical decisions are made. Let us then proceed to examine the nature of the attachment between doctor and patient.

The Burden of Responsibility

If we investigate the feelings of doctors for patients, we will discover more subtle relations than mere paternalism. There is a sensation that includes more emotional content than is generally understood by the phrase "professional responsibility," and which is evoked by knowledge of the patient's predicament. These feelings may be relieved by a favorable outcome, but become more painful when the outcome is poor, regardless of whether or not the physician has been at fault. These emotions, which

motivate the physician to improve the patient's health, are not solely derived from the desire to honor the obligations of the implicit contract, or to avoid punishment. In the language of psychiatry, these feelings would be described as a form of counter-transference.

One example of this emotionality is the desire to "save" patients. This rescue fantasy, perhaps more common among young physicians, is most in evidence when most cruelly challenged by reality, as when first a patient dies who has been in one's care. The sense of failure that arises on such occasions is too commonly experienced to be ignored as part of doctors' attachment to patients.

One source of this emotion may be the patient's vulnerability. Robert Burt gives illuminating examples of the effect of the weak on the strong. He discusses the relationship of parent and child, in which the parent has considerable authority and power, and yet is often controlled by the demands and needs of the child.⁶⁰ The apparently weaker member of a pair is not therefore without certain types of power, for the vulnerable can and do make powerful claims upon those responsible for them. Thus, though the patient is dependent upon the doctor, so is the doctor dependent upon the patient. This interdependence of doctor and patient is the most significant aspect of the attachment between them. It is an essential feature of the ethics of responsibility, yet it is impossible to

⁶⁰ Burt, p.66-7.

describe within the ethics of rights.

It may be, as Burt and other authors have argued, that we see in the weak our own past helplessness, and even more frightening to contemplate, our helplessness that is yet to be. It follows that we care for others in the way we hope to be cared for. We protect the weak because we can not bear to think of ourselves as unprotected.

More onerous responses to weakness are possible, such as avoidance and fear. One may observe on the wards the diminishing amounts of time that the health care team spends with patients who are known to be dying, and for whom a cure is no longer to be attempted. This avoidance is occasionally attributed to the desire to allow patients privacy in their last days, but also includes a measure of discomfort comprised of guilt and fear. Perhaps there is also a degree of helplessness, for when we cannot rescue, doctors are often at a loss.

What Patients Feel

As patients we learn that feelings toward our doctors can cover quite a range of emotions. In some circumstances, we see the physician as Virgil to our Dante; they are our guide through hell. Unwittingly, we lend strength to the doctor's rescue fantasy, by asking to be rescued. Our illusion is supported by the mysterious technology with which the doctor is surrounded, and by the arcane language he or she understands. This holds true even for those who are doctors, for it is entirely possible to

find oneself a complete novice when affected by a disease that lies outside one's area of expertise. Our admiration for doctors is not always, of course, unbounded. Indeed, we may experience irritation, anger and disappointment, to a degree usually reserved for family members, when doctors fall short of our expectations. This strength of emotional response testifies to the unusual nature of the bond between doctor and patient. This bond arises in part from the doctor's special access to private information about the patient. The permission to examine the patient's body, and to ask questions which are highly personal and potentially embarrassing, is unprecedented even within family relationships.

The Family

The families of very ill and incompetent patients are in a position similar in some ways to that of the doctor. They help fulfill the role of protector; they look out for the patient's interests when the patient cannot; they may be able to understand risks and options that the patient cannot comprehend. In other respects, the family becomes like a patient. They are obliged to question the doctor, and to participate in decisions in ways that competent patients do for themselves. The well-being of the family, tied to the health of its members, depends upon the doctor. There emerges from this role a strange combination of power and powerlessness.

This role is made all the more complicated by the complex

emotions that arise from the illness of a loved one. Among these are the more laudable sentiments, such as sympathy for the patient's pain, sorrow for the various limitations imposed by disability, and even sorrow for one's own potential loss. There is also the potential, however, for less praiseworthy sentiments to exist, such as resentment of the patient because of his or her dependence and the demands made on one because of it, as well as anger at the patient who may, as a result of this illness, leave the loved one behind. Also, as in the case of doctors, the sight of a helpless and suffering patient may cause family members to fear their own potentially similar fate.

Thus we see that not only judges, but patients, families, and doctors have emotions which affect the nature of the attachments between them and the decisions they make. To recognize the existence and the inevitability of emotions, is to reject the purported emotional neutrality of legalism. Medical ethics does not exist in an emotionally neutral context -- nor should it. For to deny the emotional content of the attachment of the various persons concerned for the patient's welfare is to distort the nature of these relations. Indeed, we see that emotional neutrality is one aspect of legalism which does not "fit" the context of medical dilemmas. As John Ladd has written:

...the posture of impersonality, which constitutes the strength of legalism in one context, is precisely that characteristic that renders it dysfunctional in other contexts. Medical ethics...is specifically -- perhaps uniquely -- concerned with situations in which impersonal and personal considerations overlap and are difficult to

separate from each other.⁶¹

Ladd's comment is reminiscent of Gilligan's views on detachment. When self and other are not equal, i.e., when one member of a pair is dependent on the other, detachment may imply the ability "to turn away from need."⁶² When the law aims at emotional neutrality, it distorts the nature of the bonds between us, and the responsibilities that arise from them.

Within the ethics of rights, attachment, particularly as it occurs between patients and their families and doctors, cannot be adequately described. All relationships in a legalistic system are reduced to either contractual obligations or acts of generosity which one is not bound to perform. According to Ladd:

When it comes to personal relationships of a more permanent nature, such as those between friends or between members of the same family or community, the exhaustive and exclusive division of morality into obligatory acts and acts of supererogation that typifies an ethics of rights does not seem appropriate. The morality of taking care of another person with whom one has some kind of personal relationship cannot be reduced either to an obligation corresponding to a right or to a gratuitous favor.⁶³

Thus, within the ethics of rights, it is impossible to describe responsibility and care, which are central aspects of the interdependent relationships between doctor, patient and family. In this context, where autonomous individuals demand and grant rights to one another, it is impossible to maintain a relation that is not contractual in nature. This flaw is particularly

⁶¹ Ladd, p.14.

⁶² Gilligan, Different Voice, p.25.

⁶³ Ladd, p.22.

disturbing in its implications for medicine.

Burt suggests that there would be fewer decisions to withdraw life-sustaining treatment if incompetent patients were considered with more respect. While the fear of retribution may well lead to more treatment, such excesses are not synonymous with care, but lead instead to "defensive medicine."

One indication that more treatment does not indicate more respect is in the ominous reference to the Cardiac Care Unit as the Chi-Chi U, after a disturbing joke which is popular in teaching hospitals. According to the joke, two sailors are shipwrecked on an island inhabited by savages. Both are thrown into a primitive jail. The first is brought before the king and asked, "Which do you choose: death or chi-chi?" The puzzled prisoner, knowing what death is, chooses chi-chi. Then he is dragged about the island, and subjected to a seemingly endless series of humiliations and tortures. When at last, near death, he is thrown back into the cell along with his fellow prisoner, he tells him, "When they ask you to choose death or chi-chi, choose death." Shortly thereafter, the second prisoner is brought before the king, who asks him the fateful question. Having been warned, the second prisoner of course answers, "I choose death!" "Right you are," says the king, "but first -- some chi-chi."

The implications of the joke are painful, as it is translated into the language of the wards. What physicians do to patients in the Chi-Chi Unit is not to care for them, but to

administer a series of tortures which will postpone, but not prevent, death. The same activities are also described colloquially as flogging or beating. The point of recounting this language is not to chastise the house officers who popularize it, and who perform the majority of procedures in intensive care units, but to recognize how they view their role. There is something about their duties, especially "heroic measures," that is not always consistent with the idea of care.

Perhaps this distortion of the purpose of medicine derives from the enormous emphasis placed on technology in medicine and in medical education. Along with this overvaluation of intervention and cure, even when no longer sustained by hope, there seems to be a complementary devaluation of medicine's duty to comfort the dying.

In summary, the legal approach, which has as its foundation the ethics of rights, fails to help us in resolving medical dilemmas for several reasons. Legalism cannot comprehend the nature of attachment, one of interdependence and responsibility, within which medical choice is made. The impediments to direct communication in the adversarial system prevents us from focusing on the patient. For the wholly incompetent patient, the goal of maximizing patient autonomy, which is the goal of the ethics of rights, is a harmful fiction. By pretending to see the patient who depends on us and on whom we depend as isolated, we are distracted from the task of understanding our responsibilities toward the vulnerable members of our community.

Chapter VI: The Ethics of Responsibility

Principles for Decision-Making

We have asserted that physicians' decisions must be guided by standards that are clear and accessible to public discussion. The following is an attempt to describe standards that are consistent with the ethics of care.

Rather than attempting to create formal principles, we will begin by accepting as our first principle Kant's categorical imperative, namely: "Act so as to treat man, in one's own person as well as in that of anyone else, always as an end, and never merely as a means." The ethics of responsibility consists of substantive norms which interpret this principle of respect for persons in the context of relationships. The ethics of rights also takes as its first principle the categorical imperative. However, the ethics of rights uses different substantive norms in order to explain the application of this abstract principle. What follows is a list of norms for the ethics of responsibility.

1. Respect for persons demands not only that we refrain from harming others, but also that we strive to nurture their human capacities.

2. Human capacities which demand respect include both autonomy and relationality.

3. To respect persons, we must respond to them as they

exist, not as we wish they were.

4. The form of knowledge required in order to respect persons flows from both subjective and objective information, acquired through "loving attention" (infra).

5. Moral decisions within the ethics of responsibility cannot be made simply by applying rules; such decisions also require an understanding of context, and the individuals within it.

For Kant, the categorical imperative means that we must treat other persons with respect because of their autonomy. To Kant's followers, although not necessarily to Kant, such respect has come to imply a negative form of freedom, i.e., the freedom to be left alone. Within the ethics of responsibility, respect includes positive social cooperation. We must not only keep from harming others, we must strive to further the realization of their potential.

This potential that we must nurture is a complex entity, and to understand it, we must examine our definition of persons. Kant describes autonomy as the foundation of human dignity. Margaret Farley builds on this concept by claiming that both autonomy and relationality are fundamental human qualities, and serve as the basis of our obligation to respect persons.⁶⁴ Relationality is the capacity or potential to experience other

⁶⁴ Margaret Farley, "Obligating-Features of Personhood," unpublished draft, 1982.

persons. Richard McCormick has advanced similar arguments, which we shall discuss below.⁶⁵

Although we strive to nurture both autonomy and relationality, not all persons exhibit both these attributes. When we encounter a person who lacks one or both of these attributes, it is a violation of respect to ignore this fact of their existence and treat them as if they do exhibit the attribute. A healthy infant, for instance, lacks autonomy yet experiences relation. When beings lack autonomy, yet show relational capacity, we respect them by nurturing their relational capacity. For instance, when we apply the ethics of responsibility to medicine, we see that competent patients may choose to assert their autonomy without regard for relationality. An incompetent patient, on the other hand, will always have some compromise to autonomy, but may still maintain relational attributes. For such a patient, we protect relationality; we cannot protect autonomy for one who lacks it.

It is no easy matter to estimate the capacity in a person for autonomy and relation. The effort can only be accomplished by communication founded in trust, and unfettered by suspicion and territorial claims. The necessary information develops through the process of loving attention, which is the painstaking effort to understand all relevant aspects of the patient's experience. We shall consider this concept in more detail

⁶⁵ Richard McCormick, "The Quality of Life, The Sanctity of Life," Hastings Center Report, (February, 1978), pp.30-6.

shortly.

In the ethics of responsibility, moral decisions require a knowledge of context and of subjective information. Therefore, morality cannot be reduced to a system of rules. Nonetheless, we can describe standards by which we may evaluate moral decisions, and we have listed these in the opening of this section. As our discussion continues, we will describe how these standards may be applied specifically to medicine.

A Member of the Community

The ethics of responsibility draws upon Gilligan's idea of the moral decision-maker, and the community in which he or she lives. The moral agent does not espouse the extreme form of autonomy, but sees him or herself as an integral part of a community.

In the ethics of responsibility, the community is more of a sustaining environment than a means of suppressing aggression. We will rely upon Durkheim's concept of the "collective conscience," which is a "psychic reality" vested with moral authority.⁶⁶ Although Durkheim conceives of this entity as ideal and unchanging, I prefer to redefine it as neither innate nor infallible. It evolves over time and shifts to a degree within segments of society, according to ethnicity, religion, generation, and degree of social privilege. The conscience is

⁶⁶ Emile Durkheim, The Division of Labor in Society, trans. by George Simpson, New York, The Free Press, 1933, (1893), p.78.

meant to be seen in a positive light, as a means of determining right from wrong, rather than as an instrument for meting out censure.

Rather than highlight the autonomy of individuals, the collective conscience emphasizes our interdependence, since we all contribute to its formation. We can incorporate this concept into an idea of community in which members are encouraged not just to stay out of each other's way, but to actively contribute to the well-being of all. In the rights model, the community resembles a union of states whose members select non-aggression as their goal. In the responsibility model, the community is more like an organism, which flourishes as a whole to the degree in which each component thrives. Responsibility is not what we owe to persons by virtue of the rights they may demand of us, but is our expression of membership within the community. This vision of community fits well with Gilligan's idea of moral maturity. For her, maturity is represented by one who integrates the needs of the self and of others. For a physician, this would mean striving to see clearly the needs of the patient, while not pretending to be oneself unaffected by highly emotional situations, as when a patient's death is imminent. The physician who is thus aware of emotion is not adrift in a sea of bathos, but does not ignore the presence of such feelings as sadness and pity.

Gilligan's unique description of the moral agent gives rise to a different process of moral choice. As mentioned in chapter

IV, Kohlberg depicts moral choice as occurring in an emotional vacuum. Any rational being provided with the correct data would select the correct choice. The operation does not require attachment; indeed, it flourishes in the setting of detachment. Gilligan, as well as other writers, argues that detachment is not the only way, nor necessarily the best way, to carry out moral decision-making.

Iris Murdoch offers a description of moral choice which includes the concept of love, in the form of careful attention. In "The Idea of Perfection," Murdoch suggests that moral decisions need not be the result of purely rational analysis.⁶⁷ Instead, she borrows the concept of loving attention from Simone Weil, and shows how it may be part of certain types of moral choice. "Love" in this context refers neither to erotic love nor to the love of family members for one another. It is closest to the concept of "philios," the bond of trust, loyalty, and devotion typical of life-long friends. Murdoch explains loving attention through the example of a mother-in-law, M, and her daughter-in-law, D. M at first sees D as a rather immature girl, who lacks refinement and poise. However, M suspects this unfavorable judgment may be partially motivated by jealousy. Furthermore, she wishes to treat D with respect, since she is married to M's son. Over time, M reflects upon D, and encourages herself to examine D's attributes carefully, yet respectfully. M

⁶⁷ Iris Murdoch, "The Idea of Perfection," in The Sovereignty of Good, New York, Schocken Books, 1971.

is not dishonest and does not attempt to see D as better than she is. She does pay careful attention to the way in which her evaluation of D is adversely affected by emotions like jealousy; she does not ignore emotion but looks steadfastly upon it, acknowledging its power. Through the process of this patient, gradual discipline, M learns to see D more clearly, and yet more kindly.

In the above example, Murdoch provides us with an unusual description of moral decision-making. She does not present choice as something we do all at once and dramatically. On the contrary, the subtle art of seeing persons as they are is more evident than any overt act. Nor is it possible to extract the choice and the persons concerned from their context; the relations between them make an enormous difference to the situation. Choice is the product of sustained, painstaking effort, as in the choice to be respectful to one's daughter-in-law. Moral choice is not the calculus of abstract principles, but a discernment of the interrelation between subjective and objective data, respect and need, and emotion and choice. In this sort of decision-making, attention is not a quality that can be added, but is an integral part of what makes this choice moral. It is precisely this quality of loving attention which is appropriate to the resolution of ethical dilemmas in medicine, and yet which is prevented by an atmosphere in which the threat of punishment looms large. This quality of attention is proscribed by the adversarial atmosphere encountered in court,

and recommended by George Annas. Yet it is such attention which patients deserve from us when we attempt to care for them in their most vulnerable moments.

What Murdoch is describing is a different type of knowledge than the type described by Kohlberg. Within the ethics of rights, all the necessary knowledge is publicly available. This would mean that moral choice in the real world would not be much different from that in the Heinz dilemma. One need only reduce the problem to its essence and perform the moral calculus to arrive at the right answer; any thinker would arrive at the same right answer. This description is reminiscent of the "choiceless chooser" in law, i.e., the judge who is a computer-like conduit of justice. However, according to Gilligan and Murdoch, some necessary information will be missing if we rely exclusively on this method. Vital knowledge must be acquired by loving attention to a specific object, in a specific context.

On the one hand, Murdoch tells us that morality requires attachment, and we observe that doctors and patients do indeed form attachments, rather than maintain strict emotional neutrality toward each other. On the other hand, attachment is not possible within the ethics of rights. Thus, the rights context seems not to fit the conditions of decision-making in a medical context.

Gilligan's research subjects resisted the limits imposed by hypothetical dilemmas. They hesitated to make general pronouncements without knowing the particularities of the

individual's circumstances. Subjective information, similar to that demanded by Gilligan's research subjects, and tied to the ethical, emotional, and personal details of the patient's needs, is required in decisions to withhold medical treatment.

Communication is vital to the proper functioning of the ethics of responsibility. The information required is subtle and complex, and may only be discerned with the loving attention of physician and family. Communication requires time and trust; even with these, information may be so emotionally charged that it is difficult to share. The emphasis on rights introduces adversarial feelings which serve to divide the decision-makers, and prevent communication. An emphasis on responsibility unites them in the common goal of caring for the patient.

Learning from Dax

A patient may be drastically limited in his autonomy, yet may nonetheless retain an unlimited capacity to feel pain. Such is the situation in the film Dax's Case, which documents the actual experiences of a severely burned young man. Although mentally competent, Dax was not allowed by his mother or physicians to refuse treatment for his burns, a refusal which would have resulted in fatal infection. Dax argued that he did not want to die, but that the physical and mental pain of receiving and anticipating treatment was so excruciating that he would rather die than endure it. Those who thwarted Dax's decision offered a number of arguments, including that he was

temporarily mentally incompetent because of his pain. Dax was treated and eventually went on to marry and run a successful business. Thus, by "objective criteria" one might argue that Dax's pain was worthwhile because of the good outcome. Dax, however, disagrees.

In the final scenes, filmed many years after his accident, Dax remains blind and severely limited in his physical abilities. He insists that it would have been better to let him refuse treatment and die, not because of his current disabilities, but because of the pain he endured. He argues compellingly that those who elected treatment for him were unable or unwilling to believe his statements that his pain was unendurable. He assails the logic of those who, since they could not fathom his pain, chose to disregard it. From the perspective of care, Dax's family and physicians seem to have respected neither his autonomy nor his relationality. They not only denied his ability to make a rational, independent choice, they destroyed his sense of trust, and thus his sense of connection to others.

Dax's Case is a chilling reminder of the limits of communication. We cannot truly understand the subjective experience of others, but we are not therefore relieved of the burden to try. This applies to the extremely articulate, like Dax, but no less to those whose autonomy is even more severely compromised, by virtue of mental incompetence. If we are able to ignore the coherent verbal pleas of Dax, how much easier is it to ignore the desperate gestures of the speechless patient?

A more disturbing question is that if Dax, with his clear understanding of the future which might await him, rejects his current life with pain, what must be the outlook of the patient who has no grasp of the purpose of treatment, or of its duration, or of the possible good which it may potentiate?

When we treat patients who are severely incompetent, we ought to be very clear about what we offer them, when it is they and not we, who pay the price in pain. When the benefit to be gained is great, such as a long life free from disease, and with the potential for full competence, then we feel justified in treating. However, when treatment inflicts pain, and when we cannot offer the patient fuller competence, relief from pain, or cure, we must reconsider the necessity for treatment. It is our good fortune to have a patient like Dax, who survived his tragedy, to tell us of our errors and of our cruelty. We must heed his admonishments all the more closely, for he stands in the place of so many who cannot speak.

Individual patients and families will gauge differently the amount of pain that can be born in exchange for a hoped-for benefit, and we must accommodate these variations. However, an extraordinary excess of suffering ensues when all patients are treated maximally, regardless of a vanishingly small hope for improvement.

Goals for Treatment

If we choose goals of therapy which are respectful to

patients' needs and circumstances, the task of selecting or rejecting specific treatments will be clarified. An effort to determine such goals has been made in our community, at Yale New Haven Hospital (YNHH). The policy on Do Not Resuscitate Decisions was the product of a committee appointed in 1978 by Samuel Thier, then Chairman of the Department of Medicine.⁶⁸ The committee made a series of recommendations regarding the identification and responsibilities of the attending physician, and appropriate communications between health care providers and families. The committee also recommended the classification of treatment goals into three basic categories. In Class A, patients are to receive all appropriate curative interventions and maintenance therapies:

The primary goal is to achieve arrest, remission, or cure of the basic disease process. The aims of curative therapy take priority over those of functional maintenance, which in turn hold a higher priority than those of comforting therapy.⁶⁹

Most patients, including very ill ones whose diagnosis remains uncertain, will fall into this first classification.

Classification B emphasizes the maintenance of function in patients for whom a cure is thought to be unattainable, and is also appropriate for competent patients who decline curative treatments. The goal of maintaining function supercedes both cure and comfort. This class is further subdivided, depending upon

⁶⁸ Committee on Policy for DNR Decisions, YNHH, "Report on Do Not Resuscitate Decisions," Connecticut Medicine, August, 1983, Vol. 47, No. 8.

⁶⁹ Ibid., p.479.

whether the patient is to be resuscitated in the event of cardiopulmonary arrest.

The final classification is C, in which the goal of comfort takes precedence over all others. This goal is suited to those for whom not only a cure, but the maintaining of physiologic function either can no longer be attained, or is no longer desired.

Of the legal cases we shall discuss, most would not be in category A, since the patients suffer lethal diseases for which no curative treatment could be proposed. Saikewicz is an exception since his doctors claimed to seek remission. In general, disputes arose when one party, usually the family, wished to treat the patient as if he or she were in class C. The legal cases arose from tension between the desire to cure and the responsibility to comfort.

In general, there is a presumption in favor of treatment, and this is why most patients are treated according to the goals of class A. However, this presumption may not work to the good of patients with fatal illnesses, for there are instances when treatment for other purposes than comfort is not consistent with respect.

Comfort as the Goal

The YNHH policy states that comfort is an appropriate therapeutic goal for one who is dying. There are, however, circumstances where comfort may rightfully be emphasized for

patients with fatal diseases, although death need not be imminent.

Margaret Farley, in "Obligating Features of Personhood," focuses on the person's capacity for relation.⁷⁰ Starting with Kant's notion that we must show respect for persons, Farley questions what it is about persons that is deserving of our respect. Previous authors have focused on autonomy, but Farley puts forward relationality as equally central to personhood, and therefore equally deserving of respect. Therefore, we respect persons because they are autonomous, and because they are relational. This does not imply that we need no longer respect persons who become incapable of relation and/or autonomy. We continue to respect and care for them. However, the ways in which we respect beings without autonomy or relation are different from our ways of responding to competent, relational persons. We cannot nurture autonomy and relation that no longer exist. We can strive to minimize pain and fear. The patient afflicted with a fatal illness, excluded by profound incompetence from both autonomy and relation, need not be forced to undergo painful procedures to extend biologic life. This stance would justify the removal of a respirator from an irreversibly unconscious patient, for instance.

Richard McCormick addresses this problem in a similar fashion by discussing the patient's potential, specifically the potential to participate in the life of the community. He

⁷⁰ Farley, op. cit., p.2.

states:

...life is not a value in and of itself....It is a value to be preserved precisely as a condition for other values...Since these values cluster around and are rooted in human relationships, it seems to follow that life is a value to be preserved only insofar as it contains some potentiality for human relationships.⁷¹

Thus, it is not life per se which has unconditional value, but the experiences which it makes possible. When we are confronted with a patient whose life holds no further potential, we must consider gravely whether we must pursue the extension of biologic life. What do we offer this patient in exchange for his pain? He cannot understand hope; he cannot understand the ratio of benefit to burden. The majority of such patients, however, continue to feel pain.

To refuse a life-sustaining treatment for an incapacitated patient need not mean the devaluing of that patient. Rather than an infringement of their autonomy, it is a recognition of their ineluctable dependence and vulnerability, and of our responsibility to care for them. As Father McCormick says:

While speaking in terms of 'every life' being of 'equal value' reveals a legitimate concern, (that medical treatment not be denied or withheld in a way violative of the rights of individuals) that is not the issue. Every person is of equal value. But not every life....⁷²

When Father McCormick refers to a patient whose life has no further potential, he -- like Margaret Farley -- concentrates on the relational capacity of the patient. Among those whose with

⁷¹ Richard McCormick, "To Save or Let Die," JAMA, July 8, 1974, p.175.

⁷² McCormick, "Quality of Life...", p.35.

no further potential for relation are the irreversibly unconscious. An emphasis on comfort would be appropriate for these unfortunate beings, even if death is not imminent.

Under what circumstances may patients who are neither irreversibly unconscious nor competent be cared for with comfort as the primary goal? Let us imagine a person whose communication skills are so limited that he or she is not able to understand the purpose of a medical intervention, nor its associated risks and benefits. Imagine that this person has a fatal illness, for which no curative therapy exists. The therapy in question, therefore, would necessarily be one that maintains biologic function or extends life, but could neither cure nor cause remission. Such extensions of biologic life may sometimes be considerable in duration, as for example, in Quinlan's case. Such a person would lack autonomy, yet might still retain relational capacity. In order to uphold the principle of respect for persons, therefore, we would need to protect relationality, perhaps by nurturing the patient's ability to trust. To administer painful and mysterious treatments to this incompetent patient would undermine trust, and therefore respect. If a therapy is known to be significantly painful or debilitating, it is legitimate to withhold such therapy. An example of such a circumstance would be the rejection of chemotherapy for Joseph Saikewicz.

For therapies which are not generally believed to be unduly painful, physicians in consultation with families might

legitimately begin such treatments. However, should the individual patient express -- in whatever way he or she can -- that the therapy is either physically or mentally painful, then treatment may be terminated. The rejection of surgery to reimplant a gastrostomy tube for ninety-two year old Mrs. Hier is an example in this category. The court rejected surgery for her not only because of the risk and pain of surgery, but also because simply having a gastrostomy tube in place was painful to Mrs. Hier.

The preceding argument assumes that the physician and family have determined that comfort should be the primary goal of therapy. Therefore, specific treatments are accepted or rejected on the basis of the amount of pain they cause. Some of these painless treatments could conceivably also be therapies which extend biologic life. Thus, we have accounted only for pain caused by medical interventions, and not for that associated with the patient's basic disease process, or with his or her very existence. A significant number of seriously ill patients, however, will suffer severe, chronic pain, for instance from metastatic cancer. For these patients, once we have chosen comfort as the therapeutic goal, we may responsibly decide not to continue or initiate any treatment that extends biologic life, even if the treatment itself causes no additional pain. Thus, the patient's condition is such that any efforts to extend biologic life would not be consistent with the goal of comfort. An example of a therapy in this category might be the addition of

antibiotics to pre-existing intravenous lines, in a patient with an acute infection atop a chronically painful, incurable disease. The treatment would not in itself be painful, except by prolonging the patient's agonizing life.

Within this system, there is no philosophical difference between withholding and withdrawing therapy. Specifically, there is no obligation to continue a therapy once its benefits no longer outweigh its burdens. Furthermore, no types of therapy are granted special status. Any therapy which can inflict pain, which includes all those dependent upon the insertion of needles and catheters, may be terminated. If necessary to maximize comfort, it is permissible to withdraw antibiotics, respirators, blood products, and in special circumstances, nutrition. Within the ethics of responsibility, we hope to encourage care that is consistent with respect. For those incompetent patients in whom significant improvement can no longer be expected, and for whom treatments cause substantial pain, including fear, we may morally decide to support comfort rather than biologic function, by withdrawing a painful, life-sustaining treatment. This does not imply that we abandon the patient, or that we withdraw all treatment. However, if the painful treatment is life-sustaining, death may come sooner as a result of its termination. This result is preferable to a brief extension of life punctuated by repeated or persistent, mystifying pain.

Chapter VII: John Storar

Facts of the Case

A major goal of the ethics of responsibility is to make decisions for incompetent patients according to principles that are at once more clear and more kind. We will examine the dilemma of one seriously incapacitated patient, discuss the legal decision that resulted, and then consider what alternatives might have been preferable.

John Storar, when he came to the attention of the courts, was a severely retarded 52 year old man.⁷³ He had a mental age of about 18 months. Although he was unable to speak, he communicated by means of grunts and gestures; he had been institutionalized at age five at the Newark Developmental Center in New York state. For John, institutionalization had not meant abandonment by his family, for his 77 year old mother continued to visit him, her only child, daily. Notably, John was cared for in an institutional setting by a group of physicians; no one doctor had primary responsibility for him.

In July, 1979, physicians at the facility noted blood in John's urine. After getting permission from Mrs. Storar, they conducted appropriate tests and discovered cancer of the bladder. John was treated with radiation therapy, to which his mother, as

⁷³ In the Matter of John Storar, 420 N.E.2d 64; 52 N.Y.2d 363 (1981).

his legally appointed guardian, consented. After six weeks of radiation therapy, the cancer was in remission.

John was relatively well until the following March, when his doctors once again noted hematuria. An unsuccessful attempt was made to cauterize the lesions in his bladder, in an effort to stop the bleeding. After the failure of this therapy, the physicians determined that John's cancer was "terminal," i.e., that he would die of it despite further medical or surgical intervention.

By May, John had gradually lost enough blood so that his doctors asked permission to transfuse him. Mrs. Storar at first refused, but then acquiesced. John received transfusions regularly until mid-June, by which point he required two units of blood every one to two weeks. On June 19, Mrs. Storar asked that the transfusions be discontinued; she insisted that they were extremely unpleasant to John, and that they served "only [to] prolong his discomfort."⁷⁴ His physicians claimed that the transfusions were necessary, and went to court in order to get permission to transfuse John over the objections of his legal guardian.

A hearing was held in September, by which time the cancer had metastasized to John's lungs, and "perhaps to other organs."⁷⁵ At that point, physicians estimated that John would live another two to six months.

⁷⁴ Ibid., p.260.

⁷⁵ Ibid., p.271.

The case traversed several levels of the New York state judicial system. In March, 1981, The Court of Appeals handed down what has stood as the final decision. The Appeals Court reversed the lower court, asserting that the physicians were correct, and that John should be transfused. Although he had, of course, continued to receive blood pending the appeal, John had died some months before this decision was announced.

In writing for the majority, Judge Wachtler based his opinion on certain factors. He asserted that John was functioning at "his usual level of mental and physical activity" with transfusions, that they did not cause excessive pain, and that he therefore ought to receive blood despite his mother's objections. Judge Wachtler conceded, as did all parties, that John objected to the transfusions. After receiving blood, John frequently passed large clots in his urine, and these were frightening to him, as well as painful. Judge Wachtler noted with approval that, although John displayed anxiety about his transfusions, this was treated with sedatives before the procedure.

Judge Wachtler does not comment, as Judge Jones did in the dissenting opinion, on John's increasing discomfort and hostility during the procedure, which had recently led to the use of physical restraints during the transfusions. Further, the dissenting Judge Jones noted that although John was physically still able to perform such activities as bathing himself, he was

far more withdrawn, and "ventured outside his room infrequently."⁷⁶ Thus, in deciding that John did not require transfusion, Judge Jones is swayed by his different interpretation of the "facts" of the case. He finds that John did not function at his usual level, and that the transfusions, while perhaps not "excessively" painful in a physical sense, were far from a minor intervention. Upon closer examination, we shall see that more than the facts of the case are debatable; we shall have cause to question the neutrality of the court, as well as its very suitability for deciding such matters.

A Fair Comparison?

In considering the dilemma of John Storar and those concerned with his care, Judge Wachtler naturally sought for precedents. The major precedents, however, were not cases involving retarded adults, but a series of cases involving infants. As the judge explained, "Mentally John Storar was an infant and that is the only realistic way to assess his rights in this litigation."⁷⁷ This is a new twist on a disturbing yet familiar theme.

The judge, unable to fathom what ought to be done with someone in John's unenviable situation, reduces the complexity of the problem by imagining John's situation to be otherwise. His tactic is therefore similar to that used in the Saikewicz case,

⁷⁶ Ibid., p.280.

⁷⁷ Ibid., p.275.

in which we are asked to imagine Saikewicz as magically competent for an instant, yet expecting to return to his life of profound retardation and life-threatening cancer. In both instances we are asked to turn our eyes away from the patient as he really is, and from the problem formulated as it actually is. In so doing, we refute the standards of the ethics of responsibility, which require us to see the individual accurately, in context, and through the lens of loving attention. As we shall see, details specific to John Storar's dilemma are lost in this process, substantiating the misgivings expressed by Carol Gilligan on the use of hypothetical examples. Certainly there is much to be learned by comparing any current problem with similar ones encountered previously. Problems arise, however, when one attempts to compare dissimilar instances.

A careful examination of Storar's status reveals that he is like an infant in one way, but dissimilar in many other respects. The obvious basis for the comparison is Storar's "mental age," a concept meant to indicate the retarded person's competence in a number of basic areas, such as speech or abstract thought. Storar's mental age is estimated at 18 months. We read, however, that he is able to bathe himself but not to speak, an odd combination for a "normal" 18 month old child. Storar is not atypical in this regard, for mental age is not meant to be taken literally; a severely retarded 52 year old person is not identical, even in mental capacity, to a child with the same mental age.

The most obvious and the saddest way in which Storar differs from a typical toddler is, of course, that the limits to his physical and mental capacity are not temporary. Indeed, one of the most salient characteristics of such young children is the speed at which they learn and change. John's few skills had been hard won. It took him fifty years to acquire them; his potential for further development is curtailed, by both his life-long retardation and his cancer. Thus, a profound difference between John and a healthy child is that only one has the potential for growth, and the possibility of becoming competent.

Judge Wachtler ignored these differences and decided that John was like an infant. He then based his opinion on a series of famous cases involving infants who required blood transfusions, i.e., children with erythroblastosis fetalis who were born to Jehovah's Witnesses.⁷⁸ Infants afflicted with this disease have red blood cells that are incompatible with those of their mother. When fetal cells enter the maternal circulation, the mother's blood becomes sensitized and forms antibodies capable of destroying the infant's blood cells. When these antibodies cross the placenta and enter the baby's circulation, massive numbers of red blood cells may be destroyed, and the baby may become severely, perhaps fatally, anemic. Infants have a limited ability to remove the products of blood cell degradation;

⁷⁸ See, for example, "Application of the President and Directors of Georgetown College," 331 F.2d 1000 (D.C. Cir.), certiorari denied, 377 U.S. 978 (1964); and D.C. Court of Appeals Ruling, November, 1974, regarding Janet P.

if toxic levels accumulate, the child can suffer severe brain damage. A mainstay of therapy for severe forms of the disease is to replace the child's damaged blood cells with ones compatible with the antibody, and therefore not subject to attack. If detected early, treatment is highly effective, and indeed, many healthy adults are alive today who survived this disease in infancy.

Treatment becomes difficult, however, when these infants are born to Jehovah's Witnesses, who object to transfusions. In a series of cases involving both children with erythroblastosis fetalis and adult Witnesses who required transfusion, the courts have established that a parent may refuse blood products for him or herself, but not for an infant. Among the reasons cited for this distinction, is that all persons ought to have an opportunity to fulfill their potential, and to become autonomous, competent adults. In this case, a child should be allowed to grow up and choose his own religion before he is allowed to die in keeping with its tenets.

Transfusions for John Storar, however, are radically different than transfusions for an infant with erythroblastosis fetalis. For the infants, the transfusion is curative. The child, by virtue of this treatment, once again has the potential to live a life which is normal in duration and unhampered by severe illness. In light of the great benefit to be gained, and the great harm to be avoided, the courts have determined that the wrong of treating a child over his parent's religious objections

is preferable to the consequences of not treating. In this way, the court protects the child's capacity for autonomy.

Storar, however, will receive no equivalent benefit. For him, transfusion is not curative, but merely palliative. In forcing upon him treatment which neither he nor his parent desires, we are not able to do so knowing that the reward to him will be a long healthy life. On the contrary, he may be expected to die within two to six months, despite our intervention. Neither are we preserving for him the opportunity for future autonomy. He has never been and never will be competent. We are not waiting for John Storar to grow up. Thus, in significant respects, Storar is not like an infant, and transfusion for him means something entirely different than it does for the infant with erythroblastosis fetalis. Judge Wachtler reasoned within the ethics of rights, and so strove to protect autonomy. However, John lacked this capacity. By the norms of responsibility, Judge Wachtler failed to respect John, for he did not respond to qualities which John had, but to ones which the judge wished he had.

Setting the Standard

The use of the Jehovah's Witness precedent is not the only disturbing feature of the case. The decision for Storar was handed down in tandem with that on Brother Fox, which we have discussed previously (chapter II). Judge Wachtler meant to draw a sharp distinction between the two cases, since he decided that

termination of treatment was appropriate in the case of Brother Fox, but not in the case of Storar. The substitute judgment standard was pivotal for Judge Wachtler in making the distinction. He states that:

clear and convincing proof...is required where it is claimed that a person, now incompetent, left instructions to terminate life sustaining procedures when there is no hope of recovery.⁷⁹

As we have seen, Brother Fox was in the fortunate, although extremely rare, position of having left "clear and convincing" indications of his wishes. He had expressed his beliefs repeatedly, unambiguously, and in the context of a serious discussion of moral values; and had reaffirmed his statements shortly before his final hospitalization. For all these reasons, Brother Fox's case demonstrates exactly the correct circumstances for the use of substitute judgment; we know what he would do if he could choose. Brother Fox is, of course, unusual in having established while competent such a clear representation of his beliefs.

Having determined that clear and convincing proof is required for proxy decision-making, Judge Wachtler then presents us with a fascinating inconsistency in his logic. He cites approvingly the District Attorney's claim that any patient's right to refuse treatment is "entirely personal" and may not be exercised by a third party once the patient becomes incompetent. Although the judge purports to agree with this dubious argument,

⁷⁹ In the Matter of Philip Eichner, on behalf of Joseph Fox, opinion combined with Storar, p.267.

he nonetheless allows the incompetent Brother Fox to forego treatment. He reconciles the contradiction by claiming that it is really Brother Fox himself who refused treatment, and that the judge is just carrying out his orders. In this interesting fiction, we see again Burt's "choiceless chooser." The judge denies that it is he who decides; he is merely a functionary carrying out the directives of a now silent, yet somehow still autonomous agent. Were he acting within the ethics of responsibility, it might be easier for him to acknowledge his role as a decision-maker. He would then consider the relevant subjective data, which in this case unequivocally reveals the meaning of the treatment, artificial respiration in the setting of irreversible coma, to the patient. This caring judge would see that the responsible decision was to withdraw the treatment. As it is, Judge Wachtler shields himself from the weighty responsibility of decision. He invents autonomy where none exists, and bows before it.

Unfortunately, most people who pass from lucidity into mental incompetence are not like Brother Fox, and will never have expressed their beliefs on these issues. For them, the use of substitute judgment becomes problematic. We can, for instance, rely on inference by examining the official views of their religion, if any, knowing that an individual may or may not agree with all the tenets of his faith. By careful investigation, we may thus learn enough about some once-competent patients to make the substitute judgment standard tenable for them.

But what of those who have never been competent? A man like John Storar has never had the opportunity to clearly and convincingly express any reasoned opinion. Judge Wachtler therefore correctly hesitates to use the substitute judgment standard for Storar. However, he proposes no alternative standard which might be more suitable. Specifically, he ignores the best interest standard, which does not require that the patient was once competent nor that he expressed his beliefs on this issue.

The omission of the best interest standard is telling, for it allows the judge to ignore life-long incompetence in patients like Storar. The unhappy result is that in Judge Wachtler's formulation, there is no means by which treatment may be terminated for a patient like John Storar. In the words of George Annas, the court "effectively deprives incompetents of any 'right to refuse treatment' and 'forces' them to be treated under all circumstances."⁸⁰ Having been denied mental competence by a cruel accident of Nature, Storar is now to be denied by law the option of foregoing treatment. If this decision is to be taken literally, then not only Storar, but every never-competent patient in New York state must always be treated maximally.

Professor Annas attempts to limit the damage by suggesting that we interpret the decision "narrowly," i.e., that we ignore its full scope and assume, although Judge Wachtler never says as

⁸⁰ George Annas, "Help From the Dead: The Cases of Brother Fox and John Storar," Hastings Center Report, June, 1981. p.20.

much, that it is meant to apply only to questions of transfusion.⁸¹ Although this interpretation decreases the scope of the disaster, it does nothing to make the decision more rational. Why, if it is permissible sometimes to remove a respirator, must we always transfuse? We shall return to this question below, in the section on subjectivity.

What lesson may we derive from the history of John Storar? We see that misfortune befalls those who are not like others. Judge Wachtler suggests that since Storar is incompetent, he must be like a healthy infant. On the other hand, he is an adult, and therefore must be like someone who was competent, and so had the opportunity to express views about health care. The result of this distorted thinking is a decision that might be appropriate for a Jehovah's witness infant, or a once-competent adult, like Brother Fox. Never does Judge Wachtler suggest a remedy for someone who is just like John Storar. Storar was not able to give us instructions for his care, and Judge Wachtler is unwilling to accept the responsibility of deciding for him. The result is a non-decision. Patients like Storar must always be treated maximally; there is no option to temper their treatment with care. Judge Wachtler, reasoning in the ethics of rights, has found a rule and applied it. He has flouted the norms of responsibility, however, by not perceiving how subjective information and context may undermine the validity of rules.

81 Ibid.

The Realm of the Subjective

Judge Jones, as noted previously, dissented from the majority and decided that Storar need not have been transfused. His reasons for disagreeing are most interesting. For one, he does not accept the "facts" of the case. As stated by the majority, these are that the transfusions did not cause "excessive" pain, and that Storar was functioning at his usual mental and physical level. Let us address first the question of whether or not Storar was functioning at his usual level. Judge Jones, in his dissenting summary of the facts, notes first of all that doctors knew Storar would die from his cancer in two to six months. He goes on to discuss the severe pain which metastatic bladder cancer entails, and notes that John was on chronic pain medication, for which his requirements were steadily increasing as his disease progressed. Furthermore, although John had long required extra sedation before transfusion, during more recent episodes his discomfort had increased, and he had also required physical restraints to prevent his pulling out the needle. Judge Jones also stressed that even when not being transfused, John had become more withdrawn, and "stayed far more in his room."⁸² Taking all these factors into consideration, it is hard to see how the majority of the court found John to be functioning at his "usual" level. They seem to have disregarded the impact of chronic pain and chronic pain medication, as well as the patient's increasing withdrawal, a possible result of the

⁸² Storar, p.280.

unaccustomed use of physical restraints, and the visitation upon him of a repeated, bewildering and painful procedure.

How could Judge Wachtler and his colleagues have ignored the changes in John, which Judge Jones had sensitively pointed out? They have chosen to ignore subjective aspects of John's state, such as his withdrawal, and concentrate instead on the less troubling and more objective matters of his intellectual and physical skills. Finding that John is still able to bathe himself, and that he cooperated with his nurse in lowering his pajama bottoms before an injection, they decide that he is functioning at his "usual" level. In other words, pain, fear and depression seem not to be important to Judge Wachtler in assessing the patient's state; he is concerned only with emotionally neutral "objective" measures. No wonder that Mrs. Storar came to a different conclusion. In the words of Judge Jones it was she who over John's lifetime:

had come to know and sense his wants and needs and was acutely sensitive to his best interests,...[and] had provided more love, personal care, and affection for John than any other person or institution, and was closer to feeling what John was feeling than anyone else....⁸³

Not surprisingly, John's mother found subjective criteria to be much more compelling than did Judge Wachtler in determining John's level of function. Although in his dissent Judge Jones did not find the patient's pain to be "excessive," one might argue that there was an emotional component which heightened its physical effect.

83 Ibid.

We must also recall that a procedure, or the pain associated with it, may have a very different meaning for different patients. We have discussed the ways in which transfusions for John differed from those for infants with erythroblastosis fetalis. We might also examine the ways in which transfusions for a severely retarded adult are dissimilar from those for other adults. In general, a transfusion for an adult is not extremely painful. For John, however, the procedure was more complicated. He had no way of understanding what was being done, or why. He would simply be periodically subjected to the insertion of a large gauge needle, and then be required to remain relatively immobile, without touching the needle, for a period of time that would seem lengthy to one with the mental age of eighteen months. When he expressed pain, he was not released, but rather was physically restrained. This example reminds us that when we try to determine the extent of pain for a particular patient during a procedure, it is not enough to know what most patients feel under similar conditions. We must try as best we can to discover what this patient feels. Given his extreme bewilderment, and the subtle changes in his state, I would argue that John's pain was considerably more than was conceded by the court. Although not in and of itself enough to require the termination of the transfusions, pain, both mental and physical, should have been more significant in the majority's decision. In the ethics of responsibility, such subjective information would have been central to the debate.

Interestingly, Judge Wachtler does not tell us whether or not he would have decided differently if the procedure had involved "excessive" pain. He relegates to a footnote the comment:

Whether the presence or absence of excessive pain would be determinative with respect to the continuation of a life sustaining measure need not be reached under the facts of this case.⁸⁴

From this statement we derive no clear idea of the circumstances under which Judge Wachtler would grant relief to a suffering patient by allowing the discontinuation of an invasive procedure. One has the impression, however, that such circumstances would be rare indeed.

Judge Wachtler did not, however, completely eschew subjective factors in his reasoning. A close look at his language reveals subtle yet significant emotional content in some key phrases. For instance, Wachtler tells us that:

...as one of the experts noted, transfusions are analogous to food -- they would not cure cancer, but could eliminate the risk of death from other treatable causes.⁸⁵

This statement is noteworthy in a number of ways. The expert quoted is a physician, but the opinion expressed is not strictly speaking a medical one. Instead, it is a highly subjective statement. Judge Wachtler seems not to have noticed this migration from the technical to the philosophical, and accepts the statement at face value. Upon closer examination, we

⁸⁴ Ibid., p.275.

⁸⁵ Ibid., p.275.

discover that the statement conceals two covert and highly questionable assumptions. These are, first, that food and transfusions are alike; and second, that feeding is always obligatory.

Thus, this physician draws in an uncritical fashion upon the symbolic significance of food. On a very basic level we associate being fed with being taken care of. For this reason, the termination of feeding in the critically ill, for instance through intravenous lines and gastrostomy tubes, remains controversial today. The courts have been much quicker to permit the termination of ventilatory support, antibiotics and other measures considered strictly medical, than they have been to allow the termination of feeding. However, as Lynn and Childress have pointed out, there are circumstances in which it is ethical to withhold food for the terminally ill, and a number of such cases have recently been decided in favor of termination.⁸⁶

From his comments on food, and from his decision, we must assume not only that Judge Wachtler believes food always to be necessary, but that transfusions fit into this same magical category. In that case, it is not surprising he would decide that patients must always be transfused.

Should we place transfusions in a special category, as treatments that must always be given? The judge uses some

⁸⁶ Joanne Lynn and James Childress, "Must Patients Always Be Given Food and Water," Hastings Center Report, October, 1983, pp. 17-21. For appropriate cases, see In the Matter of Mary Hier, 18 Mass. App 200 (1984), and In re Conroy, 190 N.J. Super. 453, 464 A.2d 303 (1983).

emotionally loaded language to reveal his opinion on the matter. He writes of the patient "bleeding to death," and suggests that such a thing cannot be permitted because "someone, even someone as close as a parent or sibling, feels that this is best for one with an incurable disease."⁸⁷ It is ironic that the patient was just as dead when he died from his metastatic cancer, having received his transfusions to the last, sedated and restrained.

The point is not that treatment should routinely be withheld from fatally ill patients. On the contrary, we must extend ourselves to do all we can to offer appropriate therapy for these patients. The problem is rather that the law is an extremely clumsy tool. Its processes are slow and inflexible, a point which even those who advocate extensive judicial intervention into medical dilemmas will concede. Furthermore, the law does not deliver the promised benefits of objectivity. It is blind to some important subjective matters, such as the meaning of a procedure to a particular patient. It is also unwittingly subjective when it determines, without analysis, that transfusions and food are both magically important therapies, which may not be withheld under any circumstances.

The dissenting Judge Jones is a most eloquent spokesman when he summarizes the flaws of the Storar decision, and of judicial intervention in general:

[This]...problem is one which the judicial system is unsuited and ill-equipped to solve and which should not usually be made the subject of judicial attention...The

⁸⁷ Storar, p.275.

methodology and techniques of our classic adversary system are not best suited to the resolution of the issues presented. The courts can claim no particular competence to reach the difficult ultimate decision, depending as it necessarily must not only on medical data, but on theological tenets and perceptions of human values which defy classification and calibration....⁸⁸

Thus, Judge Jones stands in direct opposition to George Annas on the merits of judicial expertise. With this recommendation, let us leave behind the legal system and its ethics of rights, and consider what benefits might have befallen John Storar had his dilemma been considered within the ethics of responsibility.

A Responsible Solution

By reasoning within the ethics of responsibility, we hope to devise for John Storar a solution which is both kinder and more clearly analyzed. What follows is a speculative account of what might have been, had the ethics of responsibility predominated in this case.

First, we will discuss the lack of clarity which permeated this dilemma. Thorough communication between parties is one essential element of the ethics of responsibility which seems to have been lacking. Although we cannot know directly what efforts were made at communication, there is considerable indirect evidence that these efforts were insufficient and ineffective.

Significantly, we learn that John had not one, but a team of physicians supervising his treatment. This fact is revealed in a footnote, by way of explaining why an institution and not an

⁸⁸ Ibid., p.277.

individual is named as a party in the case. The fact that no one person was John Storar's doctor may have had an extremely detrimental impact on communication. This possibility is recognized in the YNHH guidelines, by the insistence that a single physician be designated as the responsible party for each patient. In this case, we wonder who Mrs. Storar went to with her questions, her fears, and her invaluable knowledge of John. Which doctor devoted to John "loving attention," by spending time with him, by reflecting on his particular needs, and by learning about him from his mother? What information did the doctors lose by not establishing such relationships with the patient and his mother? I do not suggest that these were "bad" doctors, but that diffused responsibility differs from that which is primary and personal.

What evidence do we have that communication between these doctors and Mrs. Storar was poor? On an intuitive level, we suspect that good communication decreases the number of court cases. Where families make clear their desires and doctors make clear the medical possibilities, and where both are willing to focus on the needs of the patient more than the need to control the situation, it is often possible to work out solutions without judicial intervention. In this case, however, there is stronger evidence than this that communication was less than adequate. Judge Wachtler offers the following disturbing account of Mrs. Storar's testimony:

She admitted that no one had ever explained to her what might happen to him if the transfusions were stopped. She

also stated that she was not 'sure' whether he might die sooner if the blood was not replaced....⁸⁹

There are various possible explanations of this supposed gap in Mrs. Storar's understanding of the problem. Perhaps the physicians did explain to Mrs. Storar, but did so using language that she could not understand. Perhaps they explained clearly, and she repressed this unwelcome information. Or, she may have become so angry that she no longer believed what the doctor's told her. Alternatively, she may have known the truth, but have refused to baldly state to the judge that she knew her actions might shorten her son's life. Finally, it is possible that as Judge Wachtler suggests, the doctors simply never told her what might happen if the transfusions stopped, and why therefore they felt strongly about continuing them. It is almost beyond belief, but it is possible that these doctors went to court rather than discuss the possibility of death in a patient with metastatic cancer.

In fact, it seems unlikely that Mrs. Storar truly did not know the trade-off that was under consideration. Her later statements indicate that her insistence upon John's comfort was so great that she didn't care what might happen if the treatments stopped. Still, the possibility exists that this case might never have come to court if the physicians had clearly explained the medical options.

It would be unfair to suggest that only Mrs. Storar was

⁸⁹ Ibid., p.272.

lacking in information. It was from physician testimony that Judge Wachtler determined that John was functioning at his usual level. Although Mrs. Storar and at least one other witness disagreed, their statements about John's condition seem not to have been clearly heard. Perhaps assessments of such subjective matters as depression and trust were not deemed to be important.

Unfortunately, by excluding such subjective information, we see that the court lost sight of the details that made this case unique. The judge forces on this severely ill man a solution originally designed for healthy infants. More disturbing, the decision fails to take into account the fluidity of a patient's condition. No limitations are imposed on the requirement to transfuse. There is no discussion of what options are open should John's blood loss increase in rate, or for when he is clearly in his last few days of life. The implication is that there is never to be a time when it is acceptable to the court that comfort should be the goal of John's therapy.

Such rigidity seems lacking in feeling in the decision for this profoundly vulnerable man. The goals of his treatment should have been revised in keeping with the ethics of responsibility. Indeed, it appears that this is what his mother was trying to do. When his first symptoms appeared, she and the medical team agreed on the proper course to take. John had a battery of diagnostic tests. He then travelled to a separate facility to receive his series of radiation therapy treatments. His bladder was cauterized, and he received transfusions over a

six week period. It was after all these treatments, when his illness was conceded to be "terminal," that Mrs. Storar attempted to shift the focus of John's treatment from cure to comfort. She saw him as dying, although realizing the process might take as long as six months, and she wanted him to be comfortable.

The physicians seemed more concerned about what the patient would die from. In their view, his life was at risk from both cancer and hematuria, and they could make certain he did not die from hematuria. They could not, however, keep him alive. By this odd formulation, treatment becomes its own rationale. We treat what we can treat, and a low hematocrit is corrected with blood replacement. The larger goal of this treatment, however, seems not to have been clearly addressed by the physicians. Did they intend to extend biological life as long as possible, regardless of the patient's circumstances? Did they examine whether such an intent was motivated by technical, ethical or legal concerns? To what extent did they hear and respect Mrs. Storar's wish to shift the goal of treatment?

Our discussion of these matters must be speculative. We do not know if they were ever asked, let alone answered. Judging from the decision, and the stated reasons for it, we must assume that the court and the doctors acted in a way that they thought would protect the patient's rights. Since the patient was not competent to exercise any right, the effect was to prevent his mother from making a choice for him that would preclude other choices. For healthy children, we can by this method preserve

their right to make future choices. For John Storar, the result was the brief extension of a life that was confusing and painful.

As the patient became more frightened and withdrawn, it is hard to see how his rights and autonomy were strengthened. More apparent is the disservice to his relationship to his community. For John, his trust and sense of security are undermined as he approaches death. For his mother, her sense of protectiveness for her dying son is shattered, for she cannot give him the help he asks of her. Thus, the effort to protect John's rights did not make him free to enjoy his autonomy, for that he could never be. He was, however, a member of our community, able to form relationships and to trust; in this, he was like a child. And yet we were able to destroy this trust before he died, and that is the real tragedy of John Storar's dilemma.

The patient deserves our respect no less for his autonomy than for his relation to our community. The destruction of this relation is what we hope to prevent by bringing medical decisions into the ethics of responsibility.

Chapter VIII: Conclusion

We have attempted to answer two questions: how decisions for incompetent patients are made, and how they ought to be made. When we investigated the first question, we found that most medical ethicists rely on the legal model, with its emphasis on emotional neutrality, detachment, and objective information. As we looked more closely, however, we discovered that this model was inadequate. We uncovered a complex web of emotional, non-contractual relationships which link doctors, patients and families, making the pose of neutrality a false one.

Dissatisfaction with the legal model in resolving medical dilemmas exists not only within medicine, but also within the law itself. Witness, for instance, the criticism by judges of the current legal standards for decision-making for incompetent patients.

We attempted to devise a better way of deciding for these vulnerable patients by turning away from the ethics of rights, and toward the ethics of responsibility. In this new framework, we discovered a system which acknowledged that attachment is relevant to the domain of moral choice. The inclusion of attachment in moral discussions radically changed recommendations about how moral choices ought to be made. Thus, within the ethics of responsibilities, we do not emphasize negative freedoms, such as the freedom to be left alone, but look rather

to ways in which we may nurture the human capacities of members of the community.

Within the ethics of responsibility, our obligation to respect other persons does not depend on autonomy alone, but also on the capacity for relation. Thus, we respect persons for whichever of these human capacities they maintain. Respect does not mean that autonomous and non-autonomous patients must be treated exactly alike. Respect requires us to discover those goals and means of treatment which respond to the patient's actual needs. The human dignity of dying, or severely ill, incompetent patients is not protected by assaulting them with technology, if such interventions offer no realistic hope of cure or remission. We show more respect for these patients by responding to their need for relation, i.e., by providing comfort and communication to them and to those who will be diminished by their loss.

The ethics of responsibility provides us with standards which will lead us to make decisions that are principled and available for public review, yet flexible enough to respond to the needs and vulnerabilities of individuals.

Physicians will not be able to aid families and patients in making such decisions if their notion of professional responsibility focuses solely on technical expertise. These difficult decisions, which are an integral part of the physician's work, demand that we go beyond the technical and into the realm of ethics. It is not to our credit, therefore, that so

little time is devoted to the teaching of ethics to "students" of medicine, regardless of their level of training. If physicians are dissatisfied with the way in which decisions are made for incompetent patients, it is not appropriate for them to blame the courts and the legal model. We must accept the responsibility as our own, and learn to make decisions which are clear, yet kind.

Bibliography: Books

- Beauchamp, Tom, and Childress, James. Principles of Biomedical Ethics. New York: Oxford University Press, 1983.
- Burt, Robert. Taking Care of Strangers. New York: The Free Press, 1974.
- Cassell, Eric. The Healer's Art. New York: Lippincott, 1976.
- Durkheim, Emile. The Division of Labor in Society. New York: The Free Press, 1933 (1893).
- Eliot, George. Middlemarch. Middlesex, England: Penguin Books, 1985 (1871).
- Gilligan, Carol. In a Different Voice: Psychological Theory and Women's Development. Cambridge: Harvard University Press, 1982.
- Kant, Immanuel. The Philosophy of Kant. Edited by Carl Friedrich. New York: The Modern Library, 1949 (1764-95).
- Katz, Jay. The Silent World of Doctor and Patient. New York: The Free Press, 1984.
- Kohlberg, Lawrence. The Philosophy of Moral Development. San Francisco: Harper and Row, 1981.
- Mill, John Stuart. On Liberty. Middlesex, England: Penguin Books, 1976 (1859).
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Deciding to Forego Life-Sustaining Treatment. Washington, D.C.: U.S. Government Printing Office, 1983.
- Smith, David H., editor. Respect and Care in Medical Ethics. Lanham, Maryland: University Press of America, 1984.

Bibliography: Articles and Chapters

- Angell, Marcia. "The Baby Doe Rules." New England Journal of Medicine. (NEJM) Vol. 314. No. 10 (March 6, 1986) pp.642-44.
- Annas, George. "Help From the Dead." The Hastings Center Report, (HCR) (June, 1981), pp.19-20.
- "The Incompetent's Right to Die." HCR, (February, 1978), pp.21-3.
- "When Procedures Limit Rights: From Quinlan to Conroy." HCR, (April, 1985), pp.24-6.
- "Nonfeeding: Lawful Killing in CA, Homicide in NJ." HCR, (December, 1983), pp.19-20.
- Brandt, Allan. "Racism and Research: The Case of the Tuskegee Syphilis Study." HCR, (December, 1978), pp.21-9.
- Callahan, Daniel. "Autonomy: A Moral Good, Not a Moral Obsession." HCR, (October, 1984), pp.40-2.
- Capron, Alexander Morgan. "Ironies and Tensions in Feeding the Dying." HCR, (October, 1984), pp.32-5.
- Cassell, Eric J. "Life as a Work of Art." HCR, (October, 1984), pp.35-7.
- "The Nature of Suffering and the Goals of Medicine." NEJM. Vol. 306. No. 11. (March 18, 1982), pp.639-45.
- Committee on Policy for DNR Decisions, Yale New Haven Hospital. "Report on Do Not Resuscitate Decisions." Connecticut Medicine. Vol. 47. No. 8 (August, 1983), pp.477-83.
- Didion, Joan. "On Morality." Slouching Toward Bethlehem. New York: Washington Square Press, 1968.
- Farley, Margaret. "Obligating-Features of Personhood." Unpublished Draft, 1982.
- Gilligan, Carol. "Remapping the Moral Domain: New Images of the Self in Relationship." in press: Reconstructing Individualism. Edited by Ian Watt. Palo Alto, CA.: Stanford University Press, 1986.

- Gilligan, Carol, and Wiggan, Grant. "The Origins of Morality in Early Childhood Relationships." Unpublished Draft, November, 1985.
- Gillon, Raanan. "Autonomy and the Principle of Respect for Autonomy." British Medical Journal. Vol. 290. (June 15, 1985), pp.1806-8.
- "Paternalism and Medical Ethics." British Medical Journal. Vol. 290. (June 29, 1985), pp.1971-2.
- "Rights." British Medical Journal. Vol. 290. (June 22, 1985), pp.1890-1.
- Hilfiker, David. "Allowing the Debilitated to Die." NEJM. Vol. 308. No. 12 (March 24, 1983), pp.716-19.
- Jackson, David, and Youngner, Stuart. "Patient Autonomy and 'Death with Dignity.'" NEJM. Vol. 301. No. 8. (August 23, 1979), pp.404-8.
- Kass, Leon. "The Obligation of the Physician to his Patient and to his Profession." Therapaeia, (January, 1982), pp.61-4.
- Kohlberg, Lawrence, and Kramer, R. "Continuities and Discontinuities in Childhood and Adult Moral Development." Human Development. Vol.12 (1969), pp.93-120.
- Ladd, John. "Legalism and Medical Ethics." Journal of Medicine and Philosophy. Vol. 4 (March, 1979), pp.70-80.
- Lynn, Joanne, and Childress, James. "Must Patients Always Be Given Food And Water?." HCR, (October, 1983), pp.17-21.
- McCormick, Richard. "The Quality of Life, The Sanctity of Life." HCR, (February, 1978), pp.30-6.
- "To Save or Let Die." Journal of the American Medical Association. Vol. 229. No. 2. (July 8, 1974), pp.172-6.
- MacIntyre, Alisdair. "The Nature of the Virtues." HCR, (April, 1981), pp. 27-34.
- Macklin, Ruth. "Return to the Best Interests of the Child." Who Speaks for the Child. Edited by Willard Gaylin and Ruth Macklin. New York: Plenum Press, 1982.
- Marcus, Isabel, and Spiegelman, Paul. "Feminist Discourse, Moral Values, and the Law -- A Conversation". Buffalo Law Review. Vol. 34. (1985) pp.11-79.

- Morison, Robert S. "The Biological Limits on Autonomy." HCR, (October, 1984), pp.43-49.
- Murdoch, Iris. "The Idea of Perfection." The Sovereignty of Good. New York: Schocken Books, 1971.
- "Patients' Last Rights -- Termination of Medical Care -- An Analysis of New York's In Re Storar." Albany Law Review. Vol. 46 (Summer, 1982), pp.1380-1413.
- Ramsey, Paul. "The Saikewicz Precedent: What's Good For an Incompetent Patient?." HCR, (December, 1978), pp.36-42.
- Rubin, Beth. "Refusal of Life-Sustaining Treatment for Terminally Ill Incompetent Patients: Court Orders and an Alternative." Columbia Journal of Law and Social Problems. Vol. 19. (1985), pp.19-68.
- Sass, Hans-Martin. "Reichsrundschreiben 1931: Pre-Nuremberg German Regulations Concerning New Therapy and Human Experimentation." The Journal of Medicine and Philosophy. Vol. 8 (1983), pp.99-111.
- Schoeman, Ferdinand. "Parental Discretion and Children's Rights: Background and Implications for Medical Decision-Making." The Journal of Medicine and Philosophy. Vol. 10 (1985), pp. 45-61.
- Siegler, Mark. "Critical Illness: The Limits of Autonomy." HCR. (October, 1977), pp.12-15.
- Veatch, Robert. "Autonomy's Temporary Triumph." HCR, (October, 1984), pp.38-40.
- "Limits of Guardian Treatment Refusal: A Reasonableness Standard." American Journal of Law and Medicine. Vol. 9. No. 4. (1983), pp.427-68.
- Whitbeck, Caroline. "A Different Reality: Feminist Ontology." Beyond Domination: New Perspectives on Women and Philosophy. Edited by Carol Gould. Totowa, N.J.: Rowman and Allanheld, 1983.
- Younger, Stuart, and Jackson, David. "Family Wishes and Patient Autonomy: Commentary." HCR. (October, 1980), pp. 21-22.

Bibliography: Legal Documents

Matter of Mary Hier. 18 Mass. App. 200, (1984), pp. 959-966.

Matter of Philip Eichner, On Behalf of Joseph Fox, Respondent.
420 N.E. 2d 64. 52 N.Y. 2d 363, (1981); with Matter of John
Storar, pp.266-82.

YALE MEDICAL LIBRARY

Manuscript Theses

Unpublished theses submitted for the Master's and Doctor's degrees and deposited in the Yale Medical Library are to be used only with due regard to the rights of the authors. Bibliographical references may be noted, but passages must not be copied without permission of the authors, and without proper credit being given in subsequent written or published work.

This thesis by _____ has been used by the following persons, whose signatures attest their acceptance of the above restrictions.

NAME AND ADDRESS

DATE

David J. Eisen 333 Cedar St

2/2/88

Estie Jacobson 333 Cedar St

2/25/88

the [unclear] "

3/1/88

[unclear] 333 Cedar St

3/5/88

Bernstein 333 Cedar St

3/23/90

